Draft For Consultation:
Strategy for Lymphoedema in Wales
Designed for Lymphoedema

April 2009
Strategy for Lymphoedema in Wales

Designed for Lymphoedema

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Executive Summary

Lymphoedema is a chronic swelling due to lymphatic system failure. It can occur from a congenitally-determined lymphatic abnormality or from lymphatic damage by inflammation, infection, trauma, tumour, surgery or radiation. It is chronic and incurable, and requires life-long management. Lymphoedema can affect people of all ages and can occur in a limb, limbs, in the head and neck, trunk or genital area. It may not become apparent for sometime after the initial trauma or surgery and patients remain at risk of developing lymphoedema for the remainder of their lives. Lymphoedema affects individuals physically, psychologically and socially. It also has a significant impact on quality of life and the ability of individuals to undertake the activities of daily living.

Currently there is wide variation in the organisation and delivery of lymphoedema services across Wales. Some trusts have been commissioned to offer full lymphoedema services; others offer services that can only be accessed by cancer patients and then there are certain areas that do not provide services at all. Clinics range from lone practitioners to small teams; some with administration support others without. Waiting and treatment times vary as well as treatment options. This vast diversity is not a result of patient need and is not patient centered. Most people with lymphoedema go undiagnosed and untreated for long periods of time. This is a consequence of the poor level of knowledge of this disease amongst health professionals and the public.

Based on the prevalence of lymphoedema found in the South West London study\textsuperscript{17} of 1.33 per 1,000 there would be an estimate of at least 4,000 lymphoedema sufferers in Wales. However, looking at the prevalence rates for the last 5 years in the established Welsh clinics shows a rise every year and the average is currently 2 sufferers per 1,000 population. Thus in Wales, with a population of 2.9 million, at least 6,000 people may have lymphoedema.

The Welsh Assembly Government is committed to ensuring evidence-based service provision, underpinned by national and professional standards, to address the health needs of the 21st Century. The Strategy for Lymphoedema in Wales outlines a vision for lymphoedema services in Wales to improve health and well being, minimise the risks associated with lymphoedema, ensuring that patients can access the right services, while also supporting and empowering people to maximise their own independence in all areas of life. This will require the delivery, development and planning of lymphoedema services where care is proactively planned and coordinated.

This vision will be delivered by promoting healthy lifestyles, ensuring lymphoedema prevention and early interventions are further developed, and adhering to evidence-based practice as well as national and professional guidelines and standards.

The main aims of the Lymphoedema Strategy are to;
- Raise the awareness of lymphoedema and how simple treatment strategies can improve patient’s quality of life;
- Improve health and well being by empowering patients to maximise their own independence and minimise the risks associated with lymphoedema;
Integrate, develop, reconfigure, and more effectively plan and manage lymphoedema services throughout Wales in line with the new seven Local Health Boards (LHBs) structure;

Improve patient access to lymphoedema services ensuring that patients receive the right treatment at the right time by the right professional in the right place;

Provide a comprehensive preventative approach to all patients at risk of developing lymphoedema thereby reducing the demand on other NHS services;

Build on the strengths of the current tertiary and secondary care lymphoedema services integrating services across organisational boundaries into the community and primary care;

Develop and build on the currently available lymphoedema education enabling health care professionals to access local courses and to implement the acquired knowledge and skills in their own practice;

Clarify the actions needed to implement lymphoedema services across Wales and improve service delivery.

Each Local Health Board should establish or improve dedicated lymphoedema services in their localities. Specialised lymphoedema services should be placed within the hospital setting with community clinics providing less complicated management and ongoing monitoring of patients with this chronic condition. Establishing lymphoedema services does not only improve patient quality of life but decreases other associated health care costs including decreasing hospital admissions for cellulitis. Neglecting chronic oedema/lymphoedema ultimately results in a major drain on NHS resources.

The lymphoedema services could also be networked into North Wales, South East Wales and South West Wales. Clustering the services into networks will improve communication, clinical supervision, support, retention, audit, education, research and will ensure clinical governance standardization. Each Network should have a nominated lead lymphoedema professional that will ensure protocols, care pathways and standards of lymphoedema are being met. This enables patients to receive standardised appropriate treatment bringing an end to current inequity of service provision. Key issues, case studies and other solutions for improving the management of lymphoedema are highlighted throughout this document to help inform planning decisions. A number of key actions are also identified at the end of each chapter to ensure a more equitable and consistent approach to service provision across Wales.

To implement the recommendations within this document, a lymphoedema project manager should be appointed initially for two years funded by the Welsh Assembly Government. This post will coordinate and work alongside the planners in each of the seven Local Health Boards in developing new and enhancing established lymphoedema services.

This document is aimed at planners of health and social care services, providers of statutory, voluntary and independent services, and individuals living with lymphoedema as well as their families and other carers. A whole system approach is required to strengthen planning, management and partnership working across traditional organisational and professional boundaries to ensure care can be provided in the most appropriate and effective way.
Key Recommendations

1. **Appoint a lymphoedema project manager.**
   A two-year post funded by the Welsh Assembly Government which would coordinate and work alongside the planners in each of the Local Health Boards in developing new and enhancing established lymphoedema services. The main aim of this post will be to ensure equity of access for all lymphoedema sufferers. It will also coordinate education, audit and data collection across Wales and take forward the proposals in this document.

2. **Establish a lymphoedema network.**
   A Welsh network of lymphoedema services should be established. Patients with primary and non-cancer related lymphoedema should have equal access to the service. Planners and developers in each of the Local Health Boards should develop an integrated network of lymphoedema services in their board area to provide a high quality standard of care, which is realistic and achievable.

   o **Specialist Lymphoedema Clinics:** The Strategy for Lymphoedema recommends that planners and providers, as part of the lymphoedema network, should establish and develop specialist lymphoedema clinics at:

<table>
<thead>
<tr>
<th>Local Health Board</th>
<th>Hospital</th>
<th>Established/ Not</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Betsi Cadwaladr University</strong></td>
<td>Nightingale House Hospice Wrexham</td>
<td>Established</td>
</tr>
<tr>
<td></td>
<td>St Kentigern’s Hospice, St Asaph</td>
<td>Established</td>
</tr>
<tr>
<td></td>
<td>Eyri Hospital Caernarvon</td>
<td>Established</td>
</tr>
<tr>
<td><strong>Powys</strong></td>
<td>Brecon War Memorial Hospital with clinics at Newtown Hospital</td>
<td>Not established</td>
</tr>
<tr>
<td><strong>Hywel Dda</strong></td>
<td>Prince Phillip Hospital Llanelli</td>
<td>Established</td>
</tr>
<tr>
<td></td>
<td>Withybush Hospital</td>
<td>Established</td>
</tr>
<tr>
<td></td>
<td>Bronglais Hospital, Aberystwyth with clinics in Cardigan/ Newcastle Emlyn</td>
<td>Not established</td>
</tr>
<tr>
<td><strong>Abertawe Bro Morgannwg University</strong></td>
<td>Singleton Hospital, Swansea</td>
<td>Established</td>
</tr>
<tr>
<td></td>
<td>Princess of Wales Hospital Bridgend</td>
<td>Not established</td>
</tr>
<tr>
<td><strong>Cwm Taf</strong></td>
<td>Royal Glamorgan Pontypridd</td>
<td>Not established</td>
</tr>
<tr>
<td><strong>Cardiff and Vale University</strong></td>
<td>Velindre Hospital</td>
<td>Established</td>
</tr>
<tr>
<td><strong>Aneurin Bevan</strong></td>
<td>St Woolos Newport</td>
<td>Established</td>
</tr>
<tr>
<td></td>
<td>Neville Hall, Abergavenny</td>
<td>Not established</td>
</tr>
</tbody>
</table>
Five new services need to be established. Additional unqualified staff need to be incorporated into established clinics; this ultimately frees up inappropriate specialist time reducing waiting times for patients.

Lymphoedema Practitioners- In total, Wales needs 29.5 WTE qualified lymphoedema specialist/practitioners working to the agreed guidelines, care pathways and protocols. Lymphoedema practitioners can be from a variety of healthcare backgrounds but are often registered nurses or physiotherapists. In each of the lymphoedema clinics a suitable qualified skill mix would be employed from an agenda for change Band 5 to the network lead at Band 8A. There are currently 19.5WTE posts, thus an additional **10 WTE are needed**.

Lymphoedema Assistants- Wales also requires 19 WTE lymphoedema assistants and administration support. These posts will free up lymphoedema practitioners time from more routine duties and assist in data collection. Lymphoedema assistant are usually healthcare workers and clerical staff. We currently only have 5 WTE assistants thus an additional **14 WTE are necessary**.

In addition to the specialist lymphoedema clinics, it is also recommended that services should hold more local clinics if possible in community hospitals or GP surgeries or clusters. This is especially important in rural settings.

The services could also be networked in the same arrangement as the current Cancer Networks. North Wales, South East Wales and South West Wales. Each network should then have a lead lymphoedema professional. Clustering the services will improve communication, clinical supervision, support, retention, audit, education, research plus covers all clinical governance issues. Each service will also follow accepted protocols, care pathways and standards of lymphoedema referral enabling patients to receive standardised appropriate treatment bringing an end to current inequity of service provision.

### 3. Develop a lymphoedema prevention protocol for all services in Wales.
Prevention and early recognition are extremely important:

- All patients who are at risk of developing lymphoedema should be informed and be given written and verbal information on how to minimise their risk;
- Specific prevention schemes should be established in each of the services i.e. breast cancer lymphoedema prevention scheme;
- All health care professionals should be made aware on the prevention strategies for lymphoedema.

### 4. All patients suffering with lymphoedema / chronic oedema should be referred to a specialist lymphoedema service.

- All patients should be referred promptly to their local lymphoedema service using an all Wales lymphoedema referral form. Developers and planners should ensure that adequate referral pathways are in place so that referrals are appropriate and timely.
- A complete physical and psychological assessment of all patients diagnosed with lymphoedema should be undertaken using an all Wales lymphoedema assessment form.
5. **All lymphoedema services should be able to offer a comprehensive lymphoedema treatment programme where daily intensive management is available if needed.**
   - Daily intensive management (Decongestive Lymphoedema Therapy) consists of Manual Lymphatic Drainage (MLD), Multi-Layer Lymphoedema Bandaging (MLLB), skincare and exercise.
   - Treatment and management should be tailored to each individual patient’s needs, with appropriate review and reassessment.
   - Patients should be involved in their lymphoedema treatment planning process and agree mutual goals.

6. **All patients attending a lymphoedema service should be encouraged to self manage their chronic condition with support.**
   - Patients can feel more in control of their lymphoedema by performing simple tasks such as moisturising their skin and wearing compression garments.
   - The lymphoedema project manager should ensure that patient user/support groups are established within the lymphoedema network.

7. **Develop a lymphoedema education programme.**
   - Education on recognising lymphoedema/ chronic oedema should be incorporated into all healthcare professionals training.
   - All lymphoedema services should develop lymphoedema key worker education sessions for healthcare staff who regularly come into contact with lymphoedema patients i.e. on the community and in the cancer setting.
   - The lymphoedema specialists/ practitioners should be fully trained in lymphoedema management. These specialist lymphoedema courses are available locally in Wales.
   - The lymphoedema project manager should undertake an education and training needs analysis to determine the training required in each of the LHB to enable the implementation of the proposals in this report.

8. **Collection of clinical data is vital and all lymphoedema services in Wales should be using the Lymcalc computer software programme. These data can then be centrally analysed by the lymphoedema project manager.**

9. **Lymphoedema service data should be included in the NHS Wales Diagnostic and Therapy Services Waiting Times Targets.**

10. **Central purchasing of compression garments should be explored and led by the lymphoedema project manager.**
Chapter 1 - Setting the Scene

“*My legs were so swollen that I couldn’t walk, they leaked fluid, and my skin was sore and painful. I couldn’t get shoes that fitted and was so embarrassed that I never went out. Looking back I had no quality of life*” (Lymphoedema support group member)

1.1.1 Health care services are currently unsustainable with an over-reliance on historical, and often inappropriate, models of care. Action is needed to ensure resources used in primary and secondary care can prevent and decrease admissions to hospital, as well as promoting patient's own self-care. Improvements to current lymphoedema services are necessary to ensure high quality care can be provided that is supported by a workforce for sustainable, primary and community-based models of care.

1.1.2 Currently there is wide variation in the organisation and delivery of lymphoedema services across Wales. Some Local Health Boards have commissioned Trusts to offer full lymphoedema services; others offer services that can only be accessed by cancer patients and then there are certain areas that do not provide any services at all. Clinics range from lone practitioners to small teams, some with administration support, others with none. Waiting and treatment times vary as well as treatment options. This vast diversity is not a result of patient need and is not patient centered. This strategy aims to redress this variability to ensure lymphoedema services are accessible and equitable to all.

1.1.3 The main aims of the Lymphoedema Strategy are:

- Raise the awareness of lymphoedema and how simple treatment strategies could improve patient's quality of life;
- Improve the health and well being, and minimise the risks associated with lymphoedema; to support and empower patients to maximise their own independence;
- Integrate, develop, reconfigure and more effectively plan and manage lymphoedema services throughout Wales in line with the new seven Local Health Boards;
- Improve patient access to lymphoedema services ensuring that patients receive the right treatment at the right time by the right professional in the right place;
- Reduce levels of morbidity and lymphoedema-related disability;
- Provide a comprehensive preventative approach to all patients at risk of developing lymphoedema thereby reducing the demand on other NHS services;
- Build on the strengths of the current tertiary and secondary care lymphoedema services by integrating services across organisational boundaries into the community and primary care;
- Develop and build on the currently available lymphoedema education enabling health care professionals to easily access local courses to implement the knowledge and skills gained into their own practice;
- Clarify the actions needed to implement lymphoedema services across Wales and improve service delivery.
1.1.4 This document is aimed at planners, developers and commissioners of health and social care services, providers of statutory, voluntary and independent services and individuals living with lymphoedema, their families and other carers. Its purpose is to improve the health, well-being and the quality of life for lymphoedema patients in Wales. It is supported by the ‘Model and Framework for Chronic Conditions Management’ which delivers a more proactive and planned approach to managing chronic conditions across Wales.¹

1.1.5 This document has been compiled in partnership with the Welsh Association of Lymphoedema Services (WALS) and its members. WALS was established in 2001 to help steer lymphoedema provision in Wales and will continue to provide advice and support to lymphoedema personnel and commissioners on evidence based best practice to support the delivery of effective care for lymphoedema patients across Wales. This document has been built on the previous work undertaken to develop lymphoedema services in Wales led by Melanie Lewis and Eilish Lund and is based on the views of patients and lymphoedema health care professionals.

1.1.6 This document is needed to develop and improve lymphoedema services across Wales. Establishing lymphoedema services does not only improve patient quality of life but decreases other associated health care costs including decreasing hospital admissions for cellulitis. Neglecting chronic oedema/ lymphoedema ultimately results in a major drain on NHS resources.

1.1.7 Appropriate diagnosis and management of lymphoedema will save money by reducing hospital admissions and avoiding inappropriate interventions. Frequently, undiagnosed lymphoedema patients are mistakenly referred to other specialities, including vascular surgery, orthopaedics, plastic surgery and dermatology. Therefore patients are not seen by the right person, at the right time or in the right place.

1.2 What is lymphoedema?

1.2.1 Lymphoedema is a chronic swelling due primarily to a failure of lymph drainage. It arises from a congenitally-determined lymphatic abnormality or from damage to lymphatic structures by inflammation, including infection, trauma, tumours, surgery or radiation. It is chronic and incurable and requires life-long management including psychosocial support. Lymphoedema can affect people of all ages. It can occur in a limb or limbs or in the head and neck, trunk or genital area. It may not become apparent for sometime after trauma (e.g. cancer surgery) and patients remain at risk of developing clinical lymphoedema at a later stage.

1.2.2 Lymphoedema can be classified as primary or secondary lymphoedema:

**Primary lymphoedema** usually presents at puberty, rarely soon after birth. The first indication is usually swelling of the feet and ankles and is more predominant in women. Although less common than the secondary form it is often more extreme with disability being present for much of a patient’s life.²

**Secondary lymphoedema** occurs as a consequence of disruption or obstruction of the lymphatic pathways. The most prevalent secondary lymphoedema worldwide is filariasis which is most common in South East Asia affecting 120 million people worldwide. In the
UK, cancer surgery involving the lymphatic system, radiotherapy, trauma, vascular disease, cellulitis, immobility and dependency are the most common causes. The physical and psychological consequences are similar in patients with primary or secondary lymphoedema but, given the longer period of disability in primary cases, the economic consequences are greater.

**Cellulitis is both a cause and a complication of lymphoedema. The occurrence of lymphoedema varies between 10 and 19% amongst cases of cellulitis with up to 50% of patients with lymphoedema experiencing at least one bout of cellulitis.**

### 1.3 What is the impact of lymphoedema?

#### 1.3.1 Lymphoedema is well documented as being an extremely debilitating condition.

Some people with mild lymphoedema can manage their condition on their own with little support from health care professionals. If their lymphoedema is controlled, then they may only need to be reviewed in a clinic once or twice a year for a check up and renewal of their compression garments. Other patients are less able to self manage, and need intensive management to reduce, maintain and control their swelling, needing significant input from a multidisciplinary team.

#### 1.3.2 Physical Impact-

- Swelling - difficulty finding shoes/clothes that fit/ inability to wear jewellery
- 50% of patients reported pain and discomfort due to their lymphoedema
- Reduced range of movement in specific joints and mobility
- Skin changes including hyperkeratosis, fibrosis and thickened skin folds
- Decrease in muscle strength and exercise tolerance
- Difficulty in performing activities of daily living
- Leakage of lymph fluid (Lymphorrhoea)

#### 1.3.3 Psychological Impact-

- Many patients experience depression, anger and anxiety
- A feeling of helplessness and fearful about living with lower limb lymphoedema
- Significant impact on mental health
- Self esteem, self efficacy and self image may also be affected due to chronic pain
- Difficulties in social settings due to the stigma associated with their appearance and in opening up to their feelings with their family and friends

#### 1.3.4 Social- Economic Impact

- Patients with chronic oedema may become socially isolated as they are unable to interact with others, enjoy previous hobbies or work due to the debilitating swelling, decreased mobility or leaking lymph fluid.
- The overall economic impact of lymphoedema is considerable given the cost associated with health care provision, social welfare and lost income.

**Lymphoedema caused 80% of sufferers within a catchment area to be off work, 9% to change their employment status, 2% to switch jobs and 8% to give up work entirely.**
1.4. Categories of lymphoedema

1.4.1 Lymphoedema can be staged or classified in order to distinguish the extent of the problem so that a successful realistic treatment plan can be devised. The two most common models of classification used are:

1. International Society of Lymphology (ISL) Lymphoedema Staging (2003) (Table 1)
2. British Lymphology Society (2001) (Table 2)

1.4.2 The ISL lymphoedema staging is classified according to physical signs associated with the appearance of swelling. Psychosocial and psychological aspects are not considered. A patient may enter at stage 0 (latency period) and stay in that category for many years whereas another patients may progress quickly from 0 to III due to severity of oedema.

The BLS classification, which is widely used in the UK, does acknowledge quality of life issues. Although classification is useful, sometimes patients cannot fit into one category and will move frequently between BLS groups 2 and 3 depending on how well the lymphoedema is controlled.

**Table 1 - International Society of Lymphology (ISL) Lymphoedema Staging (2003) based on the German Society of Lymphology**

| Stage 0/Latent | The lymphatic vessels have sustained some damage which is not yet apparent. Transport capacity * is reduced but is still sufficient for the amount of lymph being removed
|               | Subjective complaints from patient possible
|               | No clinical evidence of lymphoedema, however a slower lymph flow is detected by lymphscintigraphy with initial dermal backflow
|               | Lymphoedema is not present but patient is classified as being at risk from developing lymphoedema. |
| Stage I       | Oedema is present
|               | Tissues are pitting, soft, and doughy
|               | Swelling reduces with elevation
|               | Little or no tissue fibrosis, negative Stemmer’s sign**. |
| Stage II      | Oedema is present
|               | No reduction of swelling on elevation
|               | Connective tissue proliferation/fibrosis
|               | Pitting becomes more difficult
|               | Positive Stemmer’s sign. |
| Stage III Lymphostatic Elephantiasis | Fibrosis and sclerosis (severe non induration) pitting
|                               | Positive Stemmer’s sign
|                               | Hyperkeratosis
|                               | Lymphangiomata
|                               | Papillomatosis
|                               | Fungal Infections. |

* Transport capacity of the lymphatic system refers to the amount of lymph which is transported by the lymphatic system utilising its maximum amplitude and frequency.

** Stemmer’s Sign is positive when a thickened skin fold at the dorsum of the fingers or toes cannot be lifted or is difficult to lift. The presence of this sign is an early diagnostic indication of lymphoedema. The absence of a Stemmer sign does not rule out the possibility of lymphoedema.
### 1.5 The strategic context for services in Wales

1.5.1 The Review of Health and Social Services in Wales by Sir Derek Wanless\(^\text{11}\) and Sir Jeremy Beecham’s Review of Local Service Delivery\(^\text{12}\) have highlighted that new ways of working are needed to deliver health and social care services that are fit for purpose in Wales. The agenda to improve health services has been set in Wales, led by *Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century.*\(^\text{13}\)

1.5.2 The improvements needed to address the lack of dedicated lymphoedema services are extensive and complex. The Model and Framework for Chronic Conditions sets out a new vision for Chronic Condition Management services in Wales, outlining what needs to change to improve services for chronic conditions management. The *Chronic Conditions Management (CCM) Service Improvement Plan - 2008-2011* identifies the actions needed to implement the CCM Model and Framework, improving prevention and the care of those living with chronic conditions as well as supporting people’s independence in all areas of life.\(^\text{1}\)

1.5.3 The Cancer Services Coordinating Group (CSCG) commissioned a second review into lymphoedema services in Wales and ‘*A Review - Lymphoedema Services in Wales*’\(^\text{14}\) was published in July 2006. Its summary stated:

- On the whole, lymphoedema sufferers are still being untreated and are not being managed effectively;

### Table 2 - British Lymphology Society (2001) classification of lymphoedema\(^\text{10}\)

<table>
<thead>
<tr>
<th>Group 1 People at Risk</th>
<th>Group 2 Mild uncomplicated lymphoedema</th>
<th>Group 3 Moderate to sever/complicated lymphoedema</th>
<th>Group 4 Oedema in advanced disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>o No clinical signs of oedema</td>
<td>o Excess limb volume &lt;20%</td>
<td>o Swelling present in the trunk, digits, or genitals</td>
<td>o Uncontrolled metastatic disease</td>
</tr>
<tr>
<td>o Risk factors for oedema can be identified</td>
<td>o No involvement in the trunk, genitals or digits</td>
<td>o Distorted limb shape</td>
<td>o Weeping/ulceration of affected limb</td>
</tr>
<tr>
<td></td>
<td>o Healthy intact skin</td>
<td>o Skin in poor condition</td>
<td>o Impaired function</td>
</tr>
<tr>
<td></td>
<td>o Normal shape</td>
<td>o Active or controlled malignancy</td>
<td>o Impaired mobility</td>
</tr>
<tr>
<td></td>
<td>o No venous or arterial complications</td>
<td>o Complications including cellulitis, lymphorrea</td>
<td>o Impaired sensation</td>
</tr>
<tr>
<td></td>
<td>o No active malignancy</td>
<td>o Moderate lymphoedema excess greater than 20% but not more than 40%</td>
<td>o Pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Severe lymphoedema 40% or more</td>
<td>o Infection</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>o Oedema of the face, genitals, head or neck</td>
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</tbody>
</table>
o The lack of appointing an all-Wales lymphoedema project manager/coordinator to integrate the services has led to little movement in the development of this ‘Cinderella’ service;

o Data collection is inadequate in certain areas leading to inaccurate prevalence and incidence figures;

o There are significant shortfalls in appointing specialist and administrative staff;

o Overall support in establishing an All Wales purchase of compression garments;

o Improve the overall awareness of lymphoedema in the NHS;

o Investigate whether the use of lymphoedema targets could be implemented.

1.5.4 In October 2006, the ‘International Consensus Best Practice for the Management of Lymphoedema’ document was produced and distributed. Its main aim is to raise the profile of lymphoedema and improve patient access to care. In February 2008, the Clinical Resource Efficiency Support Team (CREST) published Guidelines for the Diagnosis and Management of Lymphoedema. Within its recommendations, it stated that:

> ‘Each NHS Trust should establish a dedicated lymphoedema service to identify and address the needs of patients with, or at risk of developing, lymphoedema.’

Similarly, numerous NICE cancer guidelines have recommended access to lymphoedema services and are in the embryonic stages of establishing a need for their own Chronic oedema-Lymphoedema Guidelines.

The Lymphoedema Support Network (LSN) has gained support in the political arena gaining two early day motions in Westminster and is actively lobbying for NICE guidance.

1.5.5 The Welsh Assembly Government is committed to achieving high standards across the public service as set out in Making the Connections. This emphasizes the need to design and operate services around the needs of the users, not the provider, taking into account all associated risks, and ensuring high quality, easily accessible and responsive services. Strategic level partnerships, working across all organisational boundaries, are needed to agree common goals, avoid duplication and support the sustainable development of effective and responsive services. Local Health Boards and future service planning arrangements will play an increasingly important role in this context.

1.5.4 The Lymphoedema Strategy is an issue for the whole of Wales. Implementation and development of lymphoedema services will be based on the assessment of local needs and existing service providers but must be consistent with the strategic direction outlined in this document. Plans to implement and commission the key recommendations in this document will need to be considered by the seven new NHS Local Health Boards along with their local partners.

1.5.5 This strategy and recommendations will help patients at risk of lymphoedema or with primary or secondary lymphoedema have a diagnosis and treatment which is timely, effective, efficient, patient focused and with measurable outcomes.
1.6 Key principles and aims

1.6.1 This strategy focuses on the needs of people with lymphoedema and aims to ensure that:
- All patients suffering with lymphoedema or chronic oedema are given a diagnosis and referred to an appropriate local lymphoedema service;
- Patients with lymphoedema are referred for assessment in a timely manner as early intervention reduces the severity of lymphoedema;
- Patients diagnosed with lymphoedema become partners in their treatment management optimising self care and promoting independence;
- All patients experiencing lymphoedema are offered appropriate treatment strategies that are, where possible evidence based.

1.7 Planning and delivery of lymphoedema services

1.7.1 Robust planning, delivery and commissioning will need to ensure that all lymphoedema services are evidence-based, patient-centred, accessible, cost effective and responsive to the needs of lymphoedema patients. Currently, there is wide variation in the organisation and delivery of lymphoedema services across Wales. In Powys and Ceredigion, there are no specialised lymphoedema services. In South East Wales, the lymphoedema service concentrates on the cancer-related condition with the non cancer lymphoedema referrals being placed on an ever-growing waiting list.

1.7.2 Long term and sustainable services must be developed using local need acquired as an integral part of the planning and commissioning process. This will inform the development of local services and the Health, Social Care and Well-Being Strategies in partnership with service users, their carers and all key stakeholders. Consideration should also be given to what clinical outcomes are relevant and important. Evaluation and audit should be supported by information technology wherever possible for example the use of the Lymcalc lymphoedema software programme.

1.7.3 Local service users are essential in helping to determine how services can best meet their needs. Public and patient involvement including local support groups will need to be further developed to ensure patient’s experiences are discovered.
## Key elements of service planning and delivery

<table>
<thead>
<tr>
<th>Assessment of service users needs</th>
<th>Audit of current service provision in primary, secondary, tertiary and voluntary care. Review of patient needs through focus and support groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preventative action and services</td>
<td>Prevention of lymphoedema strategies across primary, secondary and tertiary care e.g. breast cancer lymphoedema prevention scheme</td>
</tr>
<tr>
<td>Public and patient engagement</td>
<td>User involvement in services Patients Support group Expert Patient Programme</td>
</tr>
<tr>
<td>Development of care pathways</td>
<td>WALS Lymphoedema Project Manager</td>
</tr>
<tr>
<td>Links with related service commissioning, provision and support</td>
<td>Welsh Assembly Government LHB WALS Lymphoedema Project Manager</td>
</tr>
<tr>
<td>Demonstration of the development of services within all four tiers of the chronic condition model</td>
<td>Health improvement and primary care prevention including practice nurses Primary care and community based services with chronic disease management teams Network based, more specialised services Complex case managed services including collaboration with other specialties</td>
</tr>
<tr>
<td>Workforce implications and planning</td>
<td>Welsh Assembly Government LHB Lymphoedema Project Manager</td>
</tr>
<tr>
<td>Monitoring and evaluation of services</td>
<td>Local Action Plans Welsh Assembly Government LHB WALS Lymphoedema Project Manager</td>
</tr>
</tbody>
</table>
Chapter 2: - Incidence and Prevalence of Lymphoedema

How common is it in Wales?

2.1 Background

2.1.1 In order to understand the impact of lymphoedema on a population it is important to have accurate information on the numbers of people suffering with the condition – the prevalence. How many new cases develop yearly gives us an idea of the incidence. However, the problem with lymphoedema is that it is a relatively newly-recognised condition- the first Welsh service having been in operation for only 13 years. This situation would lead to a lower prevalence figure and a higher than normal incidence as professionals become more aware of the condition and refer patients to services. Adding to this is the difficulty that there is no agreed international definition of lymphoedema. Additionally, many primary and secondary NHS staff do not recognise the condition, and it is often misdiagnosed or confused with other conditions.

2.2 Literature search

2.2.1 Only one study to date has reported the incidence of lymphoedema in a defined population (SW London). This study found a prevalence of 1.33 per 1,000 for all ages, increasing to 5.4 per 1,000 in the over 65 age group. Only 63% of these patients were receiving treatment for their lymphoedema. The authors commented that their calculations were likely to considerably underestimate the problem. They concluded that lymphoedema was a common but under-reported condition with prevalence similar to leg ulceration. In relation to leg ulceration, there is a 10 per 1,000 lifetime risk of leg ulcers ranging from 1.5 to 3 per 1,000 active leg ulcer cases.

2.2.2 A Norwegian paper from 1990 estimated that there would be 6,000 patients from a population of 4,600,000, using the number of patients treated in a defined area; this equates to 1.3 per 1000. A number of papers have reviewed the population and most identify incidence within a particular sub group e.g. those who have developed the condition as a result of a specific cancer treatment.

2.2.3 It must also be noted that certain areas of Wales have a higher than average elderly population. This then increases the incidence of lymphoedema further as it occurs in 8 per 1,000 in the over 65 year-olds and 14 per 1,000 in the over 75 year-olds.

2.3 Incidence and prevalence of lymphoedema by aetiology

2.3.1 On reviewing the evidence on how individual causes of lymphoedema contribute to the overall burden of the condition, a constant theme throughout the literature is evident, in that lymphoedema is a very much underestimated and underdiagnosed condition. The evidence, as would be expected, shows great variation in the type and quality of research methodology undertaken. In addition, there are a number of limitations that must be noted:

- As methods for diagnosing, measuring and assessing lymphoedema vary, the opportunity for comparing and cohorting studies is limited;
The potentially lengthy time for lymphoedema to develop limits the accuracy of short follow-up studies;
- There are few well designed studies of sufficient size and follow-up to provide accurate incidence and prevalence data;
- Much of the research was undertaken more than a decade ago, when there was very limited knowledge on lymphoedema and as such misdiagnosis is a concern and is still a current issue;
- Symptoms may be present before clinical diagnosis is possible. (Adapted from the CREST Guidelines 2008)

2.3.2 Lymphoedema is generally classified as being either primary or secondary.

**Primary Lymphoedema** is due to either congenital abnormalities or absence of lymph tissue. Three types of primary lymphoedema are recognised –
- Congenital (occurring at birth)
- Praecox (between ages of 1 and 35 years)
- Tarda (over 35 years of age).

The most common primary lymphoedema syndromes are Turner’s syndrome, Milroy’s disease, Noonan’s syndrome and Klippel-Trenaunay syndrome.

The population prevalence of primary lymphoedema is difficult to ascertain. A number of papers provide estimates which vary considerable. Incidences of between 1 in 10,000 and 1 in 33,000 have been reported and 1.5 per 100,000 in the population of under 20 year-olds as well as a suggestion that up to half of all cases of lymphoedema are primary in origin. An epidemiological study identified 2,743 patients from surgical units with lymphoedema, 36.8% of whom had primary lymphoedema.

Within the UK, local audits and service reviews also estimate between 8% and 28% of patients referred to lymphoedema services are identified as having a form of primary lymphoedema.

2.3.3 **Secondary Lymphoedema** develops as a consequence of disruption or obstruction of the lymphatic pathways. The main causes of secondary lymphoedema are listed in Table 3.
### Table 3 - Classification of Causes of Secondary Lymphoedema

<table>
<thead>
<tr>
<th>Classification</th>
<th>Example</th>
</tr>
</thead>
</table>
| Trauma and tissue damage        | o Lymph node excision  
 o Radiotherapy  
 o Burns  
 o Varicose vein surgery/harvesting  
 o Large/circumferential wounds  
 o Scarring |
| Malignant Disease               | o Lymph node metastases  
 o Infiltrative carcinoma  
 o Lymphoma  
 o Pressure from large tumours |
| Venous disease                  | o Chronic venous insufficiency  
 o Venous ulceration  
 o Post-thrombotic syndrome (DVT)  
 o Intravenous drug use |
| Infection                       | o Cellulitis/erysipelas  
 o Lymphadenitis  
 o Filariasis  
 o Tuberculosis (rare) |
| Inflammation                    | o Rheumatoid arthritis  
 o Psoriatic arthritis  
 o Dermatitis/eczema  
 o Sarcoidosis and oro-facial granulomatosis  
 o Podoconosis (non-filarial, non-infective, usually crystalline blockage of the limb lymphatics)  
 o Pretibial myxoedema (rare) |
| Immobility and Dependency       | o Dependency oedema  
 o Obesity  
 o Paralysis  
 o Sleep Apnoea |
| Artificial Lymphoedema          | o Self harm |

Adapted from: *Lymphoedema Framework. Best practice for the management of lymphoedema, International consensus.* London MEP Ltd, 2006.\(^{15}\)

**Trauma and tissue damage**

Most of the evidence relating to the incidence of lymphoedema after trauma is related to the surgical and/or radiotherapeutic treatment of melanomas, breast or genito-urinary carcinomas. In patients undergoing groin dissection, significant rates of 40-55% have been reported.\(^{29, 30}\) Scars\(^{31}\) and burns\(^{32}\) have also been linked to lymphoedema as causal factors.
2.3.4 Malignant disease

Breast cancer
The incidence of breast cancer related lymphoedema literature is perhaps the most complete and the topic of a number of reviews. The development of lymphoedema as a consequence of breast cancer or its treatment has long been recognised. The incidence ranges from 6% to 42.4% in patients who had been treated with a combination of surgery and radiation for breast cancer. The majority of opinion puts the incidence somewhere in the region of 12%–25%. However, a number of papers suggest evolving surgical techniques such as sentinel lymph node biopsy will ultimately reduce the incidence of lymphoedema in patients not requiring a full axillary clearance; however, there is little information to substantiate a population reduction in lymphoedema as a result.

Melanoma
There has been a definite link between the development of lymphoedema and malignant melanoma. Early studies place the incidence between 23% and 80%. However, with advances in treatment options including sentinel lymph node biopsy without full groin dissection, the literature indicates a reduction in incidence, to around the 20% mark although there are no randomised controlled trials to validate these claims.

Sarcoma
The incidence following wide local excision and radiotherapy is in the range of 30-50%.

Gynaecological cancers
There is a lack of reliable information on the incidence of gynaecological cancer lymphoedema and is highlighted in recent reviews. A study published in 2007 of 802 survivors identified 10% with a diagnosis of lymphoedema and 15% with symptomatic swelling. Another study in 2003 of 468 patients found an 18% incidence. The most gynaecological lymphoedema was found to be present in vulva carcinomas. The significant rates of up to 48% have been recorded. Information on cervical cancer is the most common with the incidence of lymphoedema in patients undergoing hysterectomy and radiotherapy varying from 11-50%

Genitourinary Cancers
The incidence of genitourinary cancers is largely unknown and varies according to type and location of the tumour itself. Penile carcinomas range in a reported incidence from 100% if treated with inguinal dissection to 16%-28.5% by inguinal lymphadectomy. Bladder carcinoma treated by radical radiotherapy indicates a 20% incidence of lymphoedema and if treated by radical cystectomy 10% incidence. There is limited evidence on the incidence of lymphoedema related to prostate cancers as the majority of patients presenting with swelling are palliative and are logged as such not prostate. The report of the lymphoedema services review group in Northern Ireland estimated that 10% of prostate cancer patients went on to develop lymphoedema.

2.3.5 Venous Disease
Impaired lymphatic function has been identified as a common symptom of venous disease including venous ulceration. A study in 2004, reviewing the prevalence of leg ulceration in a population of 252,000 identified 113 patients 0.45/1,000; 42% of those patients also had lymphoedema. A study of 689 leg ulcers in 555 patients, identified 17 patients in whom lymphoedema was the cause of their ulcer and an additional 11
patients for which the cause was a mix of lymphoedema and venous reflux (approx 4% related to lymphoedema). 67 This study also identified a leg ulceration population prevalence of 1.5 per 1,000 over 65 years.

2.3.6 Infection
Chronic lymphoedema is both a risk factor for and a result of erysipelas/ cellulitis. 68 Cellulitis is one the primary causes of infection-related lymphoedema. While there is scant evidence on the incidence of cellulitis, a recent Cochrane review of the literature cited a study which identified a rate of 4 to 25 cases per 10,000 in the over 65 age group. 69

In a study of 176 patients admitted to hospital with cellulitis, lymphoedema was found to be a major risk factor and was present in 18% of cases. 70 Another study suggests that cellulitis may be present in up to 50% of patients suffering from severe forms of lymphoedema as compared to 1/1000 in the general population. 71 One paper identifies cellulitis as a complication in 20-30% of lymphoedemas. 72

2.3.7 Inflammation
There is limited evidence on lymphoedema prevalence amongst patients suffering from inflammatory conditions. There have been papers that identify lymphoedema as a rare complication of dermatitis, 73 and arthritis. 74

2.3.8 Immobility and Obesity
Although there is limited evidence on immobility, weight gain and increased body mass index have been considered by some as a risk factor in developing lymphoedema. Obesity in particular is well documented as playing a causal role and is a poor prognostic factor in response to lymphoedema treatment. 75-78

2.4 How many people in Wales suffer with lymphoedema?

2.4.1 Based on the prevalence of lymphoedema found in the South west London study 17 of 1.33 per 1,000 there would be an estimate of at least 4,000 lymphoedema sufferers in Wales. However, looking at the prevalence rates for the last 5 years in the established clinics shows a rise every year and the average is currently 2 per 1,000.
2.4.2 In Wales, looking at the statistics from the Welsh Cancer Intelligence and Surveillance Unit (see Table 4), there would be up to 611 new breast cancer-related lymphoedema patients, 99 melanoma patients, up to 522 gynecology cancer patients, up to 32 penile carcinomas patients, 215 prostate cancer patients, 1-2 sarcoma patients and up to 195 bladder patients. In total, that would mean up to 1,676 new patients referred from a cancer origin annually in Wales. However, the total number of patients living with lymphoedema in Wales will be related to the survival rates for these cancers. As five-year survival rates improve, there will be implications for the requirements in lymphoedema services.

Table 4 - Incidence Estimates of Lymphoedema secondary to cancer

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>New cases per year</th>
<th>Incidence of lymphoedema</th>
<th>No of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>2,444</td>
<td>12%-25%</td>
<td>293-611</td>
</tr>
<tr>
<td>Melanoma</td>
<td>497</td>
<td>20%</td>
<td>99</td>
</tr>
<tr>
<td>Gynecology Ca</td>
<td>1,043</td>
<td>15%-50%</td>
<td>157-522</td>
</tr>
<tr>
<td>Penile Ca</td>
<td>32</td>
<td>16%-100%</td>
<td>5-32</td>
</tr>
<tr>
<td>Prostate Ca</td>
<td>2,146</td>
<td>Estimate 10%</td>
<td>215</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>3</td>
<td>30%-50%</td>
<td>1-2</td>
</tr>
<tr>
<td>Bladder Ca</td>
<td>977</td>
<td>10%-20%</td>
<td>98-195</td>
</tr>
</tbody>
</table>

2.4.3 In analysing the data from the 2004 paper where 0.45 per 1000 of the population would have leg ulcers, there would be 13,229 patients diagnosed in Wales. If 42% of them then had lymphoedema, then there would be at least 5,500 sufferers from a venous disorder.

2.4.4 In Wales, it is interesting to note that in the Wrexham/Flintshire area, where a full service has been offered for over 13 years that the incidence of lymphoedema is 1.9 per 1,000. However, on closer scrutiny the figures are 2.4 per 1,000 in Wrexham and 1.5 per 1,000 in Flintshire. This could be explained by the fact that:

- Many Flintshire patients go to Chester for their secondary care and are not referred to the Flintshire service;
- The main lymphoedema clinic is the Wrexham Service and therefore better known to the local primary care teams.

If the Wrexham figures were taken as the standard then the lymphoedema prevalence for Wales would be 7,200. In looking at the true incidence and prevalence we have based this document on 2 per 1,000 developing lymphoedema which may be a better picture. Thus in Wales with a population of 2.9 million, at least 6,000 people may have lymphoedema.
<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
</tr>
</thead>
<tbody>
<tr>
<td>By March 2011, health care planners, developers and commissioners will ensure that patients have access to lymphoedema services that are able to assess, manage and evaluate.</td>
<td>Local Health Boards Welsh Assembly Government Welsh Association of Lymphoedema Services Lymphoedema Project Manager</td>
</tr>
<tr>
<td>By March 2011, evidence based lymphoedema care pathways will be developed and implemented for use across all health care settings to manage lymphoedema and the obstacles to recovery.</td>
<td>Local Health Boards Welsh Assembly Government Welsh Association of Lymphoedema Services Lymphoedema Project Manager</td>
</tr>
<tr>
<td>By June 2010, standardised patient information leaflets on preventative strategies and self management will be easily accessible.</td>
<td>Local Health Boards Lymphoedema Services Lymphoedema Project Manager</td>
</tr>
<tr>
<td>By March 2011 education and training packages, aimed at all levels from carers through to specialists in lymphoedema will be available to support better management of lymphoedema and reduce associated risks.</td>
<td>Local Health Boards Welsh Assembly Government Welsh Association of Lymphoedema Services Lymphoedema Project Manager Educational establishments</td>
</tr>
</tbody>
</table>
Chapter 3 - Prevention and Reducing the Risk of Lymphoedema

**AIM**

*To prevent or reduce the severity of lymphoedema and related disabilities through appropriate early intervention and management*

### 3.1 Background

#### 3.1.1 The main aim is to ensure that all patients whose treatment has predisposed them to developing lymphoedema are informed of the risk. Information should be provided on preventative strategies and what to do if any signs and symptoms occur. This enables patients to be referred promptly to lymphoedema services and appropriate management initiated.

### 3.2 Cancer groups

#### 3.2.1 As lymph node surgery and radiotherapy can cause a significant amount of lymphoedema in all cancers, in some areas, strategies have been initiated to improve patient information on the potential risk of lymphoedema. The most successful initiative has been in the breast group patients.

#### 3.2.2 Breast

Since the introduction of the Sentinel Node Biopsy (SNB) in breast cancer surgery, unnecessary complete axillary lymph node clearance should have reduced. Therefore the risk of lymphoedema should in theory decrease. However, only 60% of patients would be eligible for having SNB and so far this has shown no reduction in the overall lymphoedema rate.  

With such a high incidence of breast cancer related lymphoedema, rehabilitation and prevention of lymphoedema classes were initiated in certain areas of Wales.

**In Abertawe Bro Morgannwg University Trust all patients undergoing axillary surgery are invited to attend eight, 2 hour sessions in a local leisure centre. This lymphoedema preventative programme has seen the incidence of breast cancer related lymphoedema reduce from 1 in 4 to 1 in 12 people. Patient satisfaction is extremely high with improved access and efficiency.**

**In Wrexham, Carmarthenshire and Pembrokeshire all breast cancer patients are invited to a one-off education session aimed at enabling patients to reduce the risk of lymphoedema. This has been based on the award-winning Swansea scheme.**

All breast cancer patients should be assessed prior to their breast cancer surgery and measurements taken of their upper limb volume and shoulder mobility. This gives a starting baseline and changes can then be accurately recorded. All breast cancer patients should be given written information on the risk of lymphoedema and preventative strategies including skin care, exercise and prevention of infections. To reduce the occurrence of lymphoedema like the Abertawe Bro Morgannwg scheme patients should also be followed up at 6 weeks and 1 year postoperatively.
3.2.3 Gynaecological cancers - The first Macmillan gynaecological cancer rehabilitation and prevention of lymphoedema and incontinence scheme started in October 2008 in the Abertawe Bro Morgannwg NHS Trust. The scheme will follow the same format as the award winning breast scheme and preliminary results will be made available in the summer of 2009.

3.2.4 Genitourinary and melanoma cancers - Patients within this category would definitely benefit from lymphoedema prevention classes but as yet no work has been initiated due to a lack of staffing. Information leaflets should be given routinely and could easily be adapted from work already achieved.

3.3 The management of obesity

3.3.1 The prevention and management of obesity should be a priority for all, because of the considerable health benefits of maintaining a healthy weight and the health risks associated with being overweight and obese. A healthy active lifestyle is important in preventing certain conditions and maintains independent functional capabilities. It is also one of the key implementations for the Welsh Assembly Government and has been a key priority for implementation by NICE.

Public health, NHS Managers and health professionals in all primary care settings should ensure that preventing and managing obesity is a priority, at both strategic and delivery levels.

3.3.2 Many people with lymphoedema are obese and are not aware of the benefits of exercise as well as thinking that exercise will exacerbate their condition. Evidence suggests that exercise and muscle strengthening can have an impact on function by:
CONSULTATION DRAFT – Strategy for Lymphoedema in Wales

- reducing pain and stiffness
- improving muscle strength and endurance
- maintaining cardiovascular fitness
- supporting weight reduction
- contributing to an improved sense of well being.\(^{85}\)

Obesity may also be a risk factor regarding lymphoedema development in breast cancer patients. Evidence has shown that patients are far more at risk of developing lymphoedema if they gain weight after their treatment.

3.3.3 The local situation in Wrexham has illustrated that the non-cancer lymphoedema patients have a far higher body mass index than the cancer patients. 44% of non-cancer lymphoedema patients compared to 6% of cancer lymphoedema patients have a BMI over 40 putting them into the obesity III classification. These grossly obese patients can be a manual handling risk to practitioners and are also an enormous burden on the resources of the clinic in terms of time and providing made to measure compression garments. However, by treating their lymphoedema the incidence of infections will decrease. With support from the lymphoedema service they will begin to maintain their health and improve their activity level. Therefore they are less of a drain on the primary care resources.

![Body Mass Index in Wrexham Lymphoedema Clinic](image)

<table>
<thead>
<tr>
<th>BMI Category</th>
<th>Cancer Patients (%)</th>
<th>Non-cancer Patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 - 25.9</td>
<td>20%</td>
<td>8%</td>
</tr>
<tr>
<td>26 - 30.9</td>
<td>34%</td>
<td>12%</td>
</tr>
<tr>
<td>31 - 39.9</td>
<td>40%</td>
<td>36%</td>
</tr>
<tr>
<td>40+</td>
<td>6%</td>
<td>44%</td>
</tr>
</tbody>
</table>

3.4 Management of post thrombotic syndrome

3.4.1 Prevention of lymphoedema should also include the active management of post thrombotic syndrome which can cause mild oedema to incapacitating swelling with pain and ulceration. Evidence has shown that up to 60% of patients develop this syndrome following an episode of deep vein thrombosis, but if they were issued with compression garments this reduces by 50%. Further collaboration is needed in this area.\(^{86-87}\)
3.5 Improvement in community nurse awareness

3.5.1 Improving lymphoedema knowledge among community nurses will ensure simple preventative measures are taken. Early recognition and referral will reduce the severity of lymphoedema. Not only will this lessen the input of the specialist’s time but with better education will enable the district and practice nurses to collaborate on care in the community.

All front line staff including podiatrists, health visitors, practice nurses and GPs should be able to offer basic information to at risk patients including skin care and preventative information.

In Carmarthenshire, nominated practice nurses from each of the GP surgeries have attended a workshop on the management of lymphoedema. This one-day course offered them practical support in the ongoing management of chronic oedema patients and the chance to collaborate with the lymphoedema clinic. Further workshops are planned with the district nurses.

All district and practice nurses registered on the North Wales tissue viability courses receive lymphoedema training.

3.6 Early referral from orthopaedic services

3.6.1 Patients who are waiting for hip or knee surgery may develop lower limb dependency oedema as a result of immobility due to pain and a reduction in the calf muscle pump activity. As the immobility increases the oedema can progress to such an extent that it could prevent surgery. Patients therefore referred in a timely manner to lymphoedema services can maintain and enhance as much of their mobility as possible by decreasing the dependency.

Education and close working patterns between the orthopaedic outpatients and the lymphoedema service would ensure that there would be no delay in surgery due to oedema.

3.7 The management of cellulitis

3.7.1 This disabling and painful condition occurs as both a precursor of lymphoedema and as a complication. It causes much distress which, with appropriate management of lymphoedema and prompt response to early signs of infection or inflammation, can be avoided. Approximately 29% of lymphoedema patients develop cellulitis.

3.7.2 Early recognition of cellulitis and timely treatment is paramount in the reduction of severity of existing lymphoedema. In a multivariate analysis of risk factors, the presence of lymphoedema was extremely high with a factor of 71.2.

Untreated cellulitis leads to tissue breakdown which damages the initial lymphatics and increases the risk of further cellulitis attacks.

29% of chronic oedema patients had experienced at least one episode of cellulitis and 27% of this group had at least one hospital admission for acute management with intravenous antibiotics.
3.7.3 In an audit of lymphoedema patients experiencing cellulitis in Abertawe Bro Morgannwg Trust, 41% developed this complication prior to treatment whilst only 9% occurred afterwards. Of 21 patients experiencing three or more bouts of cellulitis only two did so subsequent to treatment. Since 2004, 2,316 patients have been admitted with cellulitis in one acute hospital in Abertawe Bro Morgannwg University Trust. A large scale audit is currently underway investigating how correct antibiotic procedures could in theory reduce bed occupancy.

A patient case example in Wrexham involved hospital admission for 30 days at a cost of £7,200, followed by 112 district nursing visits and £1,500 worth of dressings. Subsequent lymphoedema specialist management over 23 clinic attendances cost £1,300 that included dressings.

Thus there would appear to be large cost savings, both personally and financially to the patient and the NHS through effective management of both cellulitis and lymphoedema.

3.7.4 Patients who experience repeated episodes of cellulitis i.e. two or more attacks per year should be prescribed with prophylactic oral antibiotics. After two years of successful prophylaxis, the antibiotics may be discontinued. However, if the cellulitis reoccurs, lifelong prophylaxis is necessary. Presently, we know that patients can be treated in an unplanned way and chronic conditions account for 80% of GP consultations. A simple measure like prescribing prophylactic antibiotics, if necessary, could prevent admissions and more chronic disease. The management of cellulitis in patients with lymphoedema should follow the British Lymphology Society antibiotic guidelines.

3.7.5 Patients who experience cellulitis, with no previous diagnosis of lymphoedema, should be assessed for swelling and referred to the lymphoedema services promptly if lymphoedema is diagnosed. Correct management of oedema can reduce the episodes of cellulitis dramatically.

3.8 Conclusion

3.8.1 Lymphoedema prevention is not difficult, it is mainly about giving those at risk information and advice on what they should do and what to avoid. In Wales, only pockets of preventative strategies have been developed due to a lack of funding in lymphoedema services. If further funding was released then all areas in Wales could be providing preventative strategies in all the designated areas.
<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
</tr>
</thead>
</table>
| By June 2010 evidence based cellulitis care pathways should be developed and implemented for use across all health care settings. | Local Health Boards  
Lymphoedema Project Manager  
Lymphoedema services |
| By July 2010 health planners and commissioners will ensure that all breast cancer patients have access to lymphoedema prevention education schemes to reduce their risk of developing lymphoedema. | Local Health Boards  
Lymphoedema Project Manager  
Breast care services  
Lymphoedema services |
| By July 2010 all lymphoedema services in conjunction with physiotherapy and dietetics should offer an active management programme for obese patients. | Lymphoedema services  
Local Health Boards  
Lymphoedema Project Manager  
Expert Patient Programme  
Health Challenge Wales  
Sports Council of Wales  
Welsh Assembly Government |
| By March 2011 lymphoedema education and training packages, aimed at all levels from carers through to specialists will be available to support better management of lymphoedema/chronic oedema and reduce associated risks. | Local Health Boards  
Lymphoedema Project Manager  
Lymphoedema services  
Education establishments |
Chapter 4 - Diagnosis and Assessment of Lymphoedema

**Aim:** To ensure a timely and appropriate assessment and diagnosis of lymphoedema to minimise physical, psychological and economic impact.

### 4.1 Diagnosis:

4.1.1 Lymphoedema is an incurable chronic condition, which progresses if left untreated. Early diagnosis will ensure that patients receive appropriate assessment and management. Lymphoedema treatment is effective at any stage of the condition but the earlier a patient is diagnosed may decrease the amount of treatment required. Improving healthcare professional’s ability to recognise and diagnose lymphoedema is essential.

4.1.2 Lymphoedema is defined as an accumulation of fluid including proteins and other elements in the tissue spaces due to an imbalance between interstitial fluid production and transport. It arises from congenital malformation of the lymphatic system or from damage to the lymphatic vessels and/or lymph nodes. Lymphoedema can be associated with pain, discomfort, heaviness, functional limitations including decrease mobility and muscle strength, disfigurement, psychological distress and an elevated risk of recurrent cellulitis.

4.1.3 Differential diagnosis of lymphoedema occurs in:

  - **Lipoedema** - which is a bilateral symmetrical fatty swelling that occurs in the lower limbs from an excessive adipose fat deposition
  - **Lipolymphoedema** - occurs when a patient originally has lipoedema but through obesity, immobility, chronic venous insufficiency or skin deterioration progresses into lymphoedema.
  - **Chronic Lymphovenous Oedema** - chronic overloading of the lymphatic system regularly occurs due to impaired venous return in the lower limbs. Initially the lymphatic system will attempt to compensate for the venous system and increase its capacity but eventually the lymphatic system will fail causing lymphovenous oedema. This frequently goes unrecognised and leads to chronic swelling, leaking lymphorrhoea, skin breakdown and ulceration, which is seen daily in primary care.

4.1.4 A thorough assessment with detailed clinical history, examination and limb measurements are the key stones to establishing a diagnosis. If a lymphoedema diagnosis is uncertain, radiological investigations such as lymphoscintigraphy may be necessary to establish a diagnosis. An accurate diagnosis of lymphoedema is essential and it is important that patients referred to the service have had other causes of oedema excluded i.e. arterial problems, cardiac failure or malignancy.

### 4.2 Assessment of lymphoedema

An accurate assessment is essential in order to treat patients with lymphoedema effectively; a holistic approach should be adopted. Prior to being referred to the lymphoedema service, the referring GP or consultant should have performed a medical assessment or initial screening investigations to exclude other medical reasons for swelling such as a history of cardiac failure, DVT, renal or arterial problems.
International consensus recommends that a multi modal assessment includes:

### 4.2.1 Medical assessment
- History of lymphoedema including onset, duration, exacerbation
- Cancer history and treatment
- Family history
- Previous oedema treatment
- History of cellulitis with number of attacks per year and if prophylactic antibiotics have been prescribed
- Pain, duration, sensation, visual analogue scales
- Past Medical History
- Drug History
- Allergies
- Social information including mobility, hobbies, occupation, and sleeping history e.g. in bed or chair
- Weight and Body Mass Index

### 4.2.2 Physical examination
- Skin and tissue changes including:
  - Hyperkeratosis (thickened brown pigmentation)
  - Skin colour (e.g. erythema; brownish pigmentation)
  - Skin temperature
  - Lymphangiomata (lymph blisters)
  - Papillomatosis (warty growths on the skin due to fibrosis)
  - Fungal infections
  - Lymphorrhoea (leakage of lymph fluid through the skin surface)
  - Pitting or non-pitting oedema
  - Skin texture (soft, hardened, shiny, taut, fibrosis, ulceration);
  - Skin folds
  - Misshapen limb
- Range of movement, mobility, muscle strength and functional ability
- Neurological deficits
- Vascular assessment including arterial vascular status if relevant
- Measurement of limb volume by
  - Circumference measurements every 4cm using a tape measure
  - Perometry

### 4.2.3 Psychological assessment
It is necessary to be aware that a diagnosis of lymphoedema, its association with cancer and being incurable can lead to significant psychosocial effects. Anxiety, depression, body image problems, reduced self esteem and motivation can be observed. Thus the lymphoedema assessment should include sufficient information that a referral to psychological or social support can be made.

### 4.2.4 What method should be used to calculate limb volume in Wales?
Ideally the method needs to be easy to use, accessible, non invasive and economical. The most common method used is circumferential limb volume measurement using a tape measure and will be adapted as the method used in Wales although ongoing training is required to ensure reliability.
4.3 Early recognition and referral criteria

4.3.1 A diagnosis of lymphoedema is given if there is a 5% difference in limb volume circumference measurements\(^9\). It is seen as good practice and recommended that patients have limbs measured prior to surgery or radiotherapy if the lymph nodes are to be involved. Changes from the base line can be recorded and are more accurate in detecting a change in fluid volume. Patients who develop a 5% difference should be referred to a lymphoedema service.

4.3.2 Patients who are known to be at risk of developing lymphoedema should be informed of this potential risk and be referred to a lymphoedema service for assessment if they complain of swelling or heaviness in the limb as well as difficulty in getting shoes or jewellery to fit. \(^{79-81}\)

4.3.3 Early referral of a lymphoedema patient decreases lymphoedema severity and the amount of treatment required. Education and training on identifying lymphoedema is therefore paramount in primary and secondary care.

4.3.4 All patients who have been identified as suffering from lymphoedema regardless of cause need to be referred to a lymphoedema service. Treatment can then be arranged within the service or working collaboratively with primary care.

4.3.5 Patients referred to a lymphoedema service need to be categorised as routine, urgent or palliative. Routine patients need to be assessed within 8 weeks of referral, urgent within 4 weeks and palliative within 5 working days. Chart 1 gives information on whether a patient is routine, urgent or palliative.
Has your patient got lymphoedema or chronic oedema?

- YES
  - Lymphoedema referral not indicated at present. Provide preventative advice to patient including:
    - Skin care (including moisturising daily)
    - Exercise (improving mobility)
    - Maintenance of a healthy body weight
  - YES
    - Has the patient had numerous episodes of cellulitis in the affected area?
    - Leaking fluid?
    - Truncal/ breast swelling?
    - Head or neck swelling?
    - Genital Oedema?
    - Severe hand swelling
    - Tick Palliative box on lymphoedema referral form
    - Will be seen within 5 days
  - NO
    - Tick Urgent on the referral form
    - Will be seen within 3 - 4 weeks

- NO
  - Tick Routine on lymphoedema referral form
  - Will be seen within 6 - 8 weeks

Pathway: Referral to a lymphoedema service
<table>
<thead>
<tr>
<th><strong>Key Actions</strong></th>
<th><strong>By Who</strong></th>
</tr>
</thead>
</table>
| By July 2010 assessment tools, referral forms and criteria should be centrally developed and implemented for use across all lymphoedema services in Wales. | Lymphoedema Project Manager  
Lymphoedema services  
Welsh Association of Lymphoedema services  
Local Health Boards |
| By September 2010 planners and developers will ensure that referral protocols and criteria are in place and supported by appropriate training across all health care settings to aid early assessment and diagnosis of lymphoedema. | Local Health Boards  
Lymphoedema Project Manager |
| By March 2011 robust evaluation must be in place identifying areas of good practice that can be disseminated across Wales and areas where improvement is needed. | Local Health Boards  
Lymphoedema Project Manager  
Lymphoedema services |
Chapter 5 - Management of Lymphoedema

Aim
To ensure that all patients with lymphoedema receive effective and efficient management of their condition, which is timely, evidence based and where possible locally accessible

5.1 Background

5.1.1 This chapter focuses on the management of lymphoedema and chronic oedema and highlights the importance of a multi-disciplinary approach to help people with the physical, psychological and economic dimensions of living with this chronic condition. The main aim is to ensure that patients can see the right professional, in the right place at the right time and receive evidence based management of the condition across all levels of the Chronic Conditions Management Model i.e. from prevention to chronic elephantastic lymphoedema. See figure 4.

5.1.2 Not all individuals will require specialist lymphoedema services therefore the care should be provided across all 4 levels of the Chronic Conditions Management Module. Further lymphoedema awareness and education must be achieved in all primary care staff to improve lymphoedema management skills. Specific training for practice and district nurses is also required to improve collaboration and to fit in with the chronic conditions model. Untreated long-standing lymphoedema can lead to functional impairment, reduced self esteem and psychological problems.\textsuperscript{95-96} Appropriate evaluation of the psychological health of the patient needs to be undertaken and referral to an appropriate service instigated.

5.1.3 All patients with a lymphoedema diagnosis should have access to effective and efficient management of the condition with the aims of treatment management being:
- Restore maximum functional independence;
- Reduce risk of infection;
- Provide long-term control of limb swelling;
- Improve limb shape;
- Maximise lymph drainage in affected areas and minimise fibrosis;
- Provide psychological support;
- Educate patients in understanding their condition and rationale for treatment;
- Promote self care and independence

5.1.4 Lymphoedema management tends to be divided into intensive (Decongestive) and maintenance treatment. Intensive treatment is specialist led and normally consists of the patient attending daily for 2/3 weeks. Each day the limbs are washed, massaged, moistenerised and multilayer lymphoedema bandaged. Intensive treatment is indicated when the oedematous limb is:
- Over 20% difference in swelling
- There is a distal to proximal distorted limb shape
- There are skin folds, damaged or ulcerated skin
- Fibrosis or hardening of the tissues
- Lymphorrhoea
- Limb is too large to fit off-the-shelf compression garments
Swelling is evident in the head, neck, trunk, breast or genitalia.

In cases where the patient is already being seen by the community nurses, the intensive treatment can be modified and the multilayer lymphoedema bandaging can be shared with the community staff. Collaboration or shared care can increase community nurses skills and fits well into the Chronic Conditions Model.

The second phase of treatment, maintenance, transfers the management from the specialist back to the patient or their carer. The patient continues to be seen at 6 monthly intervals at the lymphoedema service for the re-issuing of specialist compression garments and assessment.

<table>
<thead>
<tr>
<th>Intensive Phase</th>
<th>Maintenance Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manual lymphatic drainage (MLD)</td>
<td>Compression garments</td>
</tr>
<tr>
<td>Multilayer lymphoedema bandaging (MLLB)</td>
<td>Skin care</td>
</tr>
<tr>
<td>Skin care</td>
<td>Exercise</td>
</tr>
<tr>
<td>Exercise</td>
<td>Simple Lymph drainage (MLD if appropriate)</td>
</tr>
<tr>
<td></td>
<td>MLLB if appropriate</td>
</tr>
</tbody>
</table>

5.2 The Organisation of care

5.2.1 The Model and Framework for Chronic Conditions Management should underpin the organisation of care for lymphoedema. This will ensure the delivery of consistent treatment management of all types of patients starting at health promotion. Patients attending other mainline services should be advised on the importance of skin care, exercise and a healthy diet. If lymphoedema is suspected then patients could be managed appropriately and referred on the specialist lymphoedema service in a timely fashion.
5.2.2 Integrating services more effectively is fundamental to the future of health and social care in Wales. The Community Services Framework provides key approaches which can ensure that services are accessible and effective and meet value for money goals.

- Improved co-ordination and collaboration of services enables lymphoedema services, primary care clusters, GP’s and social services to work as a team within a defined area. E.g. shared care of lymphoedema patients undergoing intensive treatment and having social services input in the long term care of applying compression garments.

- Using shared service locations such as clusters of GP surgeries, community hospitals for joint clinics with the primary care team would enhance the knowledge of the primary care staff and share the care. Joint assessment may also be useful with the tissue viability teams and dermatology.

5.2.3 The Welsh Association of Lymphoedema Services (WALS) will develop a range of patient and health professional information, protocols and guidelines to assist the primary care teams in their decision making when assessing the suitability of the need for referral to specialist lymphoedema service. Certain groups of patients cannot be managed by the primary care teams see table below.
5.2.4 Older people, those with end of life needs, or cognitive impairment and mental health problems will need special support in the planning of their care. This may include individual communication with the community psychiatric services to organise joint visits or the palliative care teams. Co-operation with carers and social services for access to specialist clinics at convenient times, with transport organised for those with disabilities as outlined in the Disability Discrimination Act. 97

5.3 Integrating primary and secondary care services

5.3.1 Although traditionally health care intervention begins with the primary care team; the lack of diagnostic and management skills in the community has led to lymphoedema services being instigated in secondary services.2 Lymphoedema is a relatively new speciality with the first service in Wales being set up in 1995.

Due to the lack of provision of care many people presenting with lymphoedema fit into the complicated category and need specialist intervention. This is especially true of those with non-cancer related lymphoedema/chronic oedema.

With increasing awareness in primary care, referrals into lymphoedema services will continue to increase. However, if the preventative strategies are effective as in the
Abertawe Bro Morgannwg NHS Trust, the incidence of breast cancer-related lymphoedema should decrease.

5.3.2 The Wrexham lymphoedema service was set up in 1995. For the first 11 years, activity increased at a steady pace. However, in the last 2 years the service is finally levelling out. Thus if all the services in Wales were properly resourced and accepted all lymphoedema referrals, one might argue that it will take a considerable amount of time for the activity to plateau.

4.3.3 Lymphoedema services can be provided in a variety of different ways:

- **Specialist lymphoedema clinic**
  This facility should be staffed by qualified lymphoedema specialists, assisted by lymphoedema technicians or assistants with an appropriate NVQ qualification and administration skills. It should have close links with the Multi Disciplinary Team and referral criteria agreed for medical input and psychological support services. The equipment must be suitable for treating the morbidly obese and all staff has specific manual handling skills. The service should also contain lymphoedema prevention clinics for the breast cancer patient as figures are showing that this is reducing the incidence of breast cancer related lymphoedema.

- **Breast care nurse specialists**
  Breast care nurses often give advice to their breast cancer patients on the signs and symptoms of lymphoedema. In certain areas in Wales the breast care nurses have undergone specific lymphoedema training and are able to offer treatment for patients with moderate lymphoedema. In other areas the breast cancer nurses refer all their lymphoedema patients to the specialist service.
o Community/leg ulcer/tissue viability clinics
An assessment of community nurses level of knowledge of lymphoedema has shown the majority admitting to adequate to poor understanding, which demonstrates an urgent need for ongoing education and support. The lymphoedema specialist can collaborate on patients who have both a vascular and lymphatic component to their swelling and are able to advise on different lymphoedema bandaging techniques plus specialist compression garment provision.

o Prevention initiatives in residential and nursing homes for the elderly and sedentary patients.
This initiative would fit in with the aims of the Locality Network Teams for chronic conditions and with continued support and education from the lymphoedema team reduce the incidence of lymphovenous oedema in the elderly and immobile patient.

5.3.4 The management of complex lymphoedema will require specialist input this includes:

Upper limb oedema:
o All patients complaining of heaviness, reduced mobility with a history of breast cancer should be referred. Limb volume measurements are necessary and specialist software is not available to the community teams.
o All those with hand swelling
o With swelling of the trunk or breast
o History of recurrent cellulitis.
o Those patients who have had bilateral breast surgery and need to have both arms monitored.

Lower limb oedema:
o Unilateral leg swelling? cause
o Those who have skin folds, and severe skin changes including leaking lymphorrea
o Those who are unable to wear proper foot wear due to foot swelling
o The morbidly obese with recognised signs of lymphatic changes – Positive Stemmers sign, skin folds, skin changes
o History of recurrent cellulitis.

5.3.5 The interventions needed to treat this group of patients should be provided by the lymphoedema team. The clinical decision making changes daily as the swollen limb is treated and the therapist depends on clinical expertise to address the changes in limb shape. A District Nurse would not have the volume of patients to gain the experience and would therefore have difficulties in applying different foams and padding's. Shared care can be undertaken in collaboration on a named patient basis.
In the future, once the appropriate manpower and education is available locally, a Lymphoedema Link Nurse Scheme within each community health care team should be developed, to facilitate collaboration.

5.3.6 The model of care for the management of lymphoedema will depend on local and regional planning and delivery decisions. In the short term, investment is required so that all areas in Wales have lymphoedema services with adequate staffing levels.
<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
</tr>
</thead>
<tbody>
<tr>
<td>By June 2011 planners and developers should have local lymphoedema services implemented as directed by this commissioning directive in each of the specified Local Health Board areas.</td>
<td>Welsh Assembly Government Local Health Boards Lymphoedema Project Manager</td>
</tr>
<tr>
<td>By December 2010 health planners and commissioners will ensure that lymphoedema services hold community based clinics in GP clusters.</td>
<td>Local Health Boards Lymphoedema Project Manager Welsh Assembly Government Lymphoedema services</td>
</tr>
</tbody>
</table>
Chapter 6 - Facilitating and Managing Independence

Aim

To ensure that lymphoedema/chronic oedema patients and their carers become partners in their care to support self management and maximise their independence

6.1 Background

6.1.1 A key role for health and social care services, in partnership with voluntary sector organisations and others is to help people with lymphoedema, especially the non-cancer lymphoedema patients to maximise their independence. All treatment approaches should support self-management, building on the patient and carer’s developing lymphoedema knowledge. Simple strategies such as daily moisturising of their affected limb and basic exercises should be encouraged.

6.1.2 Every patient attending a lymphoedema service will be supported to maintain their lymphoedema improvements by daily wearing of their compression garments. If patients are unable to don and doff their garments then social care services are involved. If patients wear their garments daily then their lymphoedema will remain under control reducing hospital admissions for cellulitis. All lymphoedema services provide patients with knowledge and information to be as independent as possible.

6.2 Social model of disability

6.2.1 The Welsh Assembly Government has adopted the Social Model of Disability as the basis for all of its work on disability. All service planners and developers should be aware that people with lymphoedema can suffer with many symptoms including fatigue and pain on a daily basis. This makes mobility and normal activities of daily living difficult.

6.3 Improving quality of life

6.3.1 Lymphoedema is a chronic condition that cannot be cured but with specialist lymphoedema services in place significant improvements can be made to enhance quality of life and maximise independence by ensuring:

- Flexible, accessible, seamless multi-disciplinary services
- Education of the user and carer in lymphoedema management
- Support for behavioral and cognitive changes in accepting a non curable chronic condition e.g. The Expert Patient Programme.
- Help in returning to work by giving employers information on limitations and helpful working conditions.
- Encouraging a healthy lifestyle

6.4 Access to information/signposting

6.4.1 Lymphoedema awareness is improving but is still a relatively newly recognised condition. It is often associated with other conditions e.g. cancer, venous and skin disorders and obesity. Lymphoedema patients have frequently lived with the condition
for many years after being told that “there is nothing to be done”. This leads to a great deal of uncertainty and anxiety regarding their future.

6.4.2 Giving patient’s information will help them understand their condition and realise that there are others suffering with the same problems. The Lymphoedema Support Network is a national charity founded in 1991 whose main aim is to ensure that every lymphoedema patient receives a correct diagnosis and suitable level of care. Another of its objectives is to promote a network of support groups throughout the UK for people with lymphoedema.

The LSN offers its members:
- Telephone information and support line
- Quarterly newsletters
- Current information on lymphoedema research and treatment
- Fact Sheets
- Web site
- Self help videos

Information on LSN can be accessed on www.lymphoedema.org/lsn/

Healthcare professionals and other agencies need to be aware of the patient information available from LSN plus awareness and accessibility of their local lymphoedema service.

6.4.3 The British Lymphology Society (BLS) is a charitable organisation with a membership of health care professionals from various specialties who have a direct interest in promoting effective management of lymphoedema. This group of professionals alongside the LSN has been instrumental in producing a consensus document on the management of Cellulitis which is available on line for clinicians.

Information on BLS can be accessed on www.thebls.com/

6.5 Self management

6.5.1 Supporting people to self manage reduces their reliance on health and social care. To be effective during the earlier stages of assessment and management a contract (written or verbal) should be drawn up between the individual and the therapist. Patients need to be made aware that this condition is chronic and effective management will only be achieved with their input, supported by the professionals.

6.5.2 Group sessions or a lymphoedema support group are a useful way in getting patients to share their lymphoedema experiences and help new sufferers. This is also a way of reducing isolation especially for those with body image problems and mobility issues. Peer supporters reported a greater benefit in quality of life than those they helped, their confidence was increased and their perception of self changed. Breast cancer support groups can also be a captive audience for the lymphoedema therapist to educate on preventative management issues around lymphoedema.

6.5.4 A dynamic lymphoedema support group can get involved in activities such as organising fitness programmes for patient’s e.g. Tai Chi and Aqua aerobics. Support Groups are eligible to apply for funding from organisations such as local branches of

**Case Study**
The Wrexham Lymphoedema Support Group are an example of a patient group rising to the challenge by using their skills to promote healthy living for their peers and approaching local organisations for help. In 2008, they received a grant from
- Sports Council of Wales for £1,000 towards the cost of aqua aerobics at the local pool
- £1,000 from Health Challenge Wales/Wrexham for a Healthy Living and weight loss programme.
- £10,000 from the Association of Voluntary Organisations Wrexham towards equipment for the lymphoedema clinic

### 6.6 Public and patient involvement

#### 6.6.1.
Involving service users is crucial to developing services that meet patients’ needs. User involvement is a key principle within the *Designed for Life* document. People with lymphoedema should be fully engaged in contributing to service design, location and implementation of the service. When the Local Health Boards plan and deliver new services it is vital that people with lymphoedema are fully engaged.

### 6.7 Personal assistance and social care

#### 6.7.1
Lymphoedema patients who need personal assistance should have responsive and flexible services. This is particularly relevant for people who have undergone a course of intensive lymphoedema treatment and are fitted with compression garments which needs applied and removed daily. The continuing management of chronic lymphoedema is only successful if the compression garments are applied correctly every day. Courses of treatment should not commence until agreement has been reached on who is going to apply the garments e.g. patient, carer or a social services care package.

### 6.8 Informal carers

#### 6.8.1
Many people living with lymphoedema are supported by informal carers. Those with severe lymphoedema resulting in very large oedematous limbs, frequently suffering with cellulitis can suffer feelings of helplessness, irritation and anger, which can be directed at their family or carers.

Informal carers can suffer with fatigue and injury; this is especially true of carers who are at risk of manual handling injuries in caring for the morbidly obese lymphoedema patients. It is essential that unpaid carers have access to support and information if their contribution to the care is to be maximised.
6.9 Social inclusion

6.9.1 In a study of 823 lymphoedema patients, 80% had time off work and 9% gave up work because of the condition. Retention in work and back-to-work programmes are important in securing a future in employment for people with lymphoedema. Work conditions (standing or sitting still for long periods) can exacerbate lymphoedema and advice to employers on types of work and duration of certain activities can lessen the difficulties for the individual.

6.9.2 The Department of Work and Pensions has produced a green paper *A New Deal for welfare: Empowering People to Work*. This document proposes a new gateway to benefits for people with illness and includes the provision of in work support to ensure people continue working.

<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
</tr>
</thead>
<tbody>
<tr>
<td>By December 2010, individual patient care plans will include a category for self management, for access to weight reduction programmes and Expert Patient Programmes</td>
<td>LHBs, Expert Patient Programmes, Local Authorities Voluntary Organisations, WALS</td>
</tr>
<tr>
<td>By July 2010 appropriate information and support on lymphoedema/chronic oedema will be widely available signposting services provided by health care providers</td>
<td>LHBs, Voluntary Sectors, Expert Patient Programme, WALS</td>
</tr>
<tr>
<td>By December 2010 unpaid carers will be actively involved in joint care planning to help them look after the patient and ensure they are working safely to prevent stress or injury to themselves</td>
<td>LHBs, Social Services, Voluntary Sector, Lymphoedema Services</td>
</tr>
</tbody>
</table>
Chapter 7 - Education, Audit and Research

7.1 Education and professional development

7.1.1 The British Lymphology Society’s Framework for Education (2001) outlines the skills needed for management of the different stages of lymphoedema.

Education should be delivered on three levels:
1. **All health care professionals**
   - Identifying those at risk of developing lymphoedema and offer preventative advice including promoting good skin care and encouraging patients to be more active.
   - Ensure they have a general awareness of lymphoedema to recognise the condition and refer on to the lymphoedema services where necessary.

2. **A key worker network** should be developed with the appropriate education to ensure that all primary care teams have a staff member who is competent in the management of mild to moderate lymphoedema. These key workers will also be collaborating in the shared care protocols in multilayer lymphoedema bandaging.

3. **All lymphoedema specialists** should have access to continuing education. They should attend a specialist course at degree/masters level from one of the recognised schools of lymphoedema management and ensure that their clinical competencies are updated regularly.

7.1.2 As lymphoedema presents as a complication of many conditions that are seen in primary, secondary and tertiary care, all health care professionals should have a basic awareness of chronic oedema lymphoedema. A rolling programme of lymphoedema education sessions should be developed and be readily available in each of the Local Health Board areas for all staff.

7.1.3 A key-worker education study programme should be in place in a local education centre/University with accredited courses at Certificate and Diploma level. A Key worker course is available at the Abertawe Bro Morgannwg University NHS Trust and is in the planning stages in North Wales.

All lymphoedema key workers will need to be competent in assessment and multi layer bandaging and have their skills updated on a 3-yearly basis.

7.1.4 Lymphoedema specialists will need to have achieved a qualification in lymphoedema management or be willing to undertake a course of study. The lymphoedema management course will also include a qualification in Manual Lymphatic Drainage. Specialist lymphoedema management courses are also run in Abertawe Bro Morgannwg University NHS Trust on an annual basis.

7.2 Competencies and skills

7.2.1 Lymphoedema specialists need to update their clinical competencies every two years following a formal qualification in one of the recognised training schools. This should include:
- Skills to treat complicated lymphoedema
- Carry an active caseload
- Provide education
o Liaise with other specialties
o Review critical incidents
o Partake in audit of their service

7.3 Audit

7.3.1 Improving the knowledge base for lymphoedema within Wales is vital to facilitate the collection of more accurate information to strengthen service development. Audit must be the key tool in monitoring the planned improvement in lymphoedema services. The audit trial should follow the patient from diagnosis to treatment and into the maintenance phase of lymphoedema management.

The services should be audited against the recommendations and standards set out in this document.

7.3.2 Developing a lymphoedema audit programme for all of Wales should fulfill the following objectives:
   1. To identify gaps in service and thereby address the inequity currently prevailing in Wales
   2. To support future commissioning, development and planning across Wales
   3. To standardise clinical practice through the implementation of evidence based guidelines
   4. To ensure that increased awareness is supported by continuing education
   5. To strengthen multidisciplinary working.

7.3.3 Audit topics should be identified by the Welsh Association of lymphoedema Services, concentrating initially on:
   o Information available for Health Care Professionals
   o Ease of access to services
   o Audit tools should be developed with a view to reducing the risk of developing lymphoedema in the Breast and Gynae cancer group of patients
   o Patient satisfaction questionnaires
   o Management of Cellulitis
   o Referral and assessment documentation audit throughout Wales
   o Delayed transfers of care and discharges due to chronic oedema

7.4 Quality of Life (QOL) Tools

7.4.1 Health-related quality of life measures are mainly two types, general and condition specific. A review of the literature has demonstrated that lymphoedema being a chronic, complex and multi-faceted condition has physical, psychological and social implications for the patients. In Wales, at present QOL tools are not used as part of a regular assessment in the clinical setting, however it is accepted that a reliable tool could supplement other outcome measures such as changes in limb volume. As yet, there is no condition-specific QOL chronic oedema tool routinely used either for research or clinical use. There are some tools described in the literature and validated but further work is needed to establish them for use in the clinical setting. The QOL tool LYMQUOL was designed for routine use in clinical practice and is in the process of validation but maybe a possibility for future use.
7.5 Research

7.5.1 Improving the knowledge base is vital in lymphoedema, in gaining more valuable information. Research on the non-cancer lymphoedemas is very important to underpin service development and ascertain true incidence. Therefore research and audit should be undertaken in partnership with relevant educational institutions.

<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
</tr>
</thead>
</table>
| By March 2011 lymphoedema education and training packages, aimed at all levels from carers through to specialists will be available to support better management of lymphoedema/ chronic oedema and reduce associated risks. | Local Health Boards  
Lymphoedema Project Manager  
Lymphoedema services  
Education establishments |
| By July 2011 the lymphoedema project manager should undertake an education and training needs analysis to determine the training required in each of the LHB enabling the implementation of the proposals in this report. | Local Health Boards  
Lymphoedema Project Manager  
Lymphoedema services  
Education establishments |
| By July 2010 the lymphoedema project manager will have completed an audit of lymphoedema patients gaining access to assessment, treatment, cellulitis, and prevention schemes. | Local Health Boards  
Lymphoedema Project Manager  
Lymphoedema services |
| By March 2011 Lymphoedema services should have completed an audit of referrals and a documentation audit on assessment forms. | Lymphoedema Services  
Lymphoedema Project Manager |
Chapter 8 - Lymphoedema service in Wales

8.1 Background

8.1.1 The first Welsh lymphoedema service commenced in 1995 in Wrexham and immediately accepted all types of lymphoedema referrals. They currently have an active case load of over 600 patients and receive just over 200 new referrals every year.

8.1.2 There are currently seven dedicated specialist lymphoedema services in Wales. Areas that do not have specialist services are Powys, Ceredigion and Bridgend. The South East Wales lymphoedema service based in Velindre Hospital covers a huge unmanageable area and is massively under-resourced. Patients have to travel long distances, the primary/non cancer lymphoedema patients are not suitably supported or treated and there is no dedicated accommodation in Velindre. Realistically, this service needs to be divided into manageable Local Health Board areas- Aneurin Bevan, Cwm Taf and Cardiff and Vale with additional resources. The South East Service does not accept the primary/non-cancer lymphoedema patients routinely and has an ever increasing waiting list. Some patients have been on the waiting list since the service commenced over ten years ago.

<table>
<thead>
<tr>
<th>Lymphoedema Service</th>
<th>Base</th>
<th>No of qualified staff</th>
<th>No of support staff</th>
<th>Current case load</th>
<th>Number of new referrals per year</th>
<th>WTE versus caseload should be</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wrexham/Flintshire</td>
<td>Nightingale House Hospice Wrexham</td>
<td>2.5</td>
<td>1</td>
<td>603</td>
<td>203</td>
<td>1:251</td>
</tr>
<tr>
<td>Conwy/Denbighshire</td>
<td>St Kentigern Hospice, St Asaph</td>
<td>1</td>
<td></td>
<td>300</td>
<td>126</td>
<td>1:300</td>
</tr>
<tr>
<td>Gwynedd/Anglesey</td>
<td>Eyr Hospital Caernarvon</td>
<td>2</td>
<td></td>
<td>217</td>
<td>79</td>
<td>1:109</td>
</tr>
<tr>
<td>South East Wales</td>
<td>Velindre Hospital</td>
<td>5.5</td>
<td>1</td>
<td>2600</td>
<td>337</td>
<td>1:473</td>
</tr>
<tr>
<td>Swansea, Neath Port Talbot</td>
<td>Singleton Hospital</td>
<td>3.8</td>
<td>1</td>
<td>841</td>
<td>280</td>
<td>1:222</td>
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<td>Carmarthenshire</td>
<td>Prince Phillip Llanelli, Mynydd Mawr and Singleton</td>
<td>2.4</td>
<td>1.3</td>
<td>520</td>
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<tr>
<td>Pembrokeshire</td>
<td>Withybush Hospital</td>
<td>1.6</td>
<td>1</td>
<td>282</td>
<td>163</td>
<td>1:176</td>
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</table>

8.1.3 In Ceredigion, the breast care nurse has undergone specific lymphoedema training and does offer assessment and treatment for these patients. In Powys, Usk House has developed a breast cancer lymphoedema prevention clinic. Thus breast cancer patients in these areas gain some treatment but neither offers a lymphoedema service for all patients. Some Local Health Boards have funded lymphoedema patients to be seen by
private lymphoedema specialists from individual patients commissioning grants. This costly intervention could in theory provide money towards developing needed lymphoedema services. Currently patients residing in Ceredigion, Rhondda Cynon Taf and Bridgend utilise private providers.

8.2 Number of lymphoedema patients treated in Wales

8.2.1 The current data has been provided by each of the established lymphoedema services and includes the *ad hoc* sessions in other areas. Currently 5,489 patients are registered as having lymphoedema in Wales. Of those, 4,367 are cancer related and 1,122 are primary or non-cancer related. These data are based on the best available information to the lymphoedema clinics as there is no specific hospital returns to capture this data at present.

8.2.2 In reviewing the data for the last 5 years, lymphoedema referrals are significantly increasing. In clustering the services into networks we can see that the case load growth is occurring throughout Wales. This data activity is only collated on patients seen and is likely to be a huge underestimation on the total prevalence of lymphoedema in Wales as the South East service does not routinely accept the non-cancer referrals.

8.2.3 Most Local Health Boards have recognised that lymphoedema services need to be further developed and would be keen to develop and expand services subject to the availability of additional funding.

8.3 Waiting times and targets

8.3.1 The Welsh Association of Lymphoedema Services collects annual data on numbers of patients waiting for an appointment. On March 31st 2007, 294 patients were waiting for appointments. This number has reduced slightly in 2008 with 244 patients waiting. This would appear to demonstrate that there is unmet need for lymphoedema patients.
8.3.2 On the whole, data collection on lymphoedema is inadequate throughout Wales. No universal or agreed data set is in existence thus patient needs, waiting times and demands on services are only done at a local level.

8.3.3 Although targets are used extensively throughout the NHS, there are none for lymphoedema services. Data on numbers of patients, waiting times needs to be addressed urgently as if there were targets actions could be placed. Therefore lymphoedema services should be included in the NHS Wales Diagnostic and Therapy Services Waiting Times Targets. This would then give valuable information to the Welsh Assembly Government.

8.4 Lymphoedema service provision- What is needed?

8.4.1 Correct diagnosis and treatment is of fundamental importance in any model of service. Patients and health care professionals need to be more aware of symptoms and early recognition. The Model and Framework for Chronic Conditions sets out a new vision for Chronic Condition Management services in Wales, outlining what needs to change to improve services for chronic conditions management. The Chronic Conditions Management (CCM) Service Improvement Plan - 2008-2011 identifies the actions needed to implement the CCM Model and Framework, improving prevention and the care of those living with chronic conditions as well as supporting people’s independence in all areas of life.

8.4.2 Each Local Health Board should establish or improve dedicated lymphoedema services in their localities. Lymphoedema services should be placed in hospital trusts within their area but local community clinic should also be established. Services should operate on a daily basis on week days. New services that need to be created include:

<table>
<thead>
<tr>
<th>Local Health Board</th>
<th>Hospital</th>
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<tr>
<td>Powys</td>
<td>Brecon War Memorial Hospital with clinics at Newtown Hospital</td>
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<tr>
<td>Hywel Dda</td>
<td>Bronglais Hospital, Aberystwyth with clinics in Cardigan/ Newcastle Emlyn</td>
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<tr>
<td>Abertawe Bro Morgannwg</td>
<td>Princess of Wales Hospital Bridgend</td>
</tr>
<tr>
<td>Cwm Taf</td>
<td>Royal Glamorgan Pontypridd</td>
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<tr>
<td>Aneurin Bevan</td>
<td>Neville Hall, Abergavenny</td>
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8.4.3 The lymphoedema services should also be networked in the same arrangement as the current Cancer Networks i.e. North Wales, South East Wales and South West Wales. Clustering the services into networks will improve communication, clinical supervision, support, retention, audit, education, research plus covers all clinical governance issues.

Each Network should have a nominated lead lymphoedema professional that will ensure protocols, care pathways and standards of lymphoedema are being met. This enables patients to receive standardised appropriate treatment bringing an end to current inequity of service provision.
8.4.4 There is general agreement that the number of lymphoedema patients per therapist if treating cancers and primary lymphoedema should be 150. This has been based on the chronic and severe nature of the condition and therapists maintaining their expertise by seeing a high volume of patients. As can be seen in 8.1.2 the WTE versus caseloads in every service bar one is well over the guidelines of 1:150. The biggest staffing ratio is in South East Wales where one therapist sees 473 patients, nearly three times the recommended number. Lymphoedema services should also operate with an appropriate skill mix, including lymphoedema assistants and administration staff. Modernising lymphoedema delivery will call for innovation in developing new roles, optimising existing roles, the development and expansion of skills and competencies.

8.4.5 Based on the prevalence figures of 2 per 1000, it is recommended that Wales needs 29.5 WTE qualified or training lymphoedema specialist/practitioners working to the agreed guidelines, care pathways and protocols. These qualified members of staff will be of a suitable skill mix from band 5 to band 8A. 19.5 WTE posts already exist thus an additional 10 WTE are required.

8.4.6 It is recommended that Wales needs 19 WTE lymphoedema assistants and administration support. These posts will free up lymphoedema practitioners time from more routine duties and assist in the data collection. We currently only have 5 WTE assistants thus an additional 14 WTE are considered necessary.
8.4.7 To implement the recommendations within this document, a lymphoedema project manager should be appointed initially for two years funded by the Welsh Assembly Government. This post will coordinate and work alongside the planners in each of the seven Local Health Boards in developing new and enhancing established lymphoedema services. The main aim of this post will ensure equity of access for all lymphoedema sufferers. It will also coordinate education, audit and data collection across Wales and take forward the proposals in this document. A lymphoedema implementation group should also be developed.

8.4.8 It is recognised that improvements to lymphoedema services in Wales is not going to happen overnight but is dependent on the availability of additional financial resources.

8.5 Resources

8.5.1 Lack of treatment for lymphoedema patients can lead to:
- Increased swelling,
- Pain,
- Tissue and skin breakdown,
- Irreversible damage to the lymphatics
- Recurrent infections
- Admissions to hospitals
- Inability to work
- Reduced psychological well being and quality of life

A number of papers have reported that potential costs savings can be realised from more effective management of lymphoedema patients particularly in relation to hospital admissions for cellulitis, wasted prescriptions and community nurse staffing costs. In one of the acute hospitals in the Abertawe Bro Morgannwg University Trust, 2,316 patients have been admitted with a cellulitis diagnosis since 2004. Appropriate lymphoedema management should also improve quality of life issues thus increasing their ability to work and reducing associated disability benefits.

8.5.2 Capital investments will be necessary to ensure that accommodation is available for the lymphoedema services. For services to function at full capacity, suitable clinic
space needs to be available daily during the week. Expenditure will also be needed for calculators and IT equipment to enable collection of data and to facilitate audit.

8.5.3 In order to provide a high standard of lymphoedema care, additional staff and services need to be developed. The recruitment of 24 WTE in total will enable all patients with lymphoedema to access lymphoedema services regardless of cause ending the current patchy and inequity of services.

8.5.4 In order to maximise the efficiency and effectiveness of the lymphoedema services, an all Wales purchasing of garments needs to be explored. At present no fixed discounts occur with each of the compression garment manufacturers and limited negotiations have transpired. Abertawe Bro Morgannwg service has managed to gain discounts that other services have not. This would also help with meeting financial governance requirements – as would greater attention to the resources wasted as a consequence of the failure to prevent development of lymphoedema and cellulitis.

8.5.5 Compression garments are the mainstay of lymphoedema management and patients are issued with hosiery every 4 to 6 months. Prices of garments vary from an arm sleeve at £20 to a mad- to-measure pair of tights at £350. This is usually dependent on the type of material and class of garment required. Not all garments are available of prescription but some are which could be suitable for the ‘at risk groups’ and mild lymphoedemas. Training is urgently needed to teach primary care staff on the different types of garments available.

8.5.6 Resources will be needed for education programmes for all health care professionals including primary care and cancer teams. Appropriately trained district and practice nurses plus GP’s will have an important role in identifying the unmet need in the community.

8.6 Conclusion

8.6.1 Lymphoedema is a physically, psychologically and socially debilitating life-long chronic condition that affects 2% of the population. Treatment enables patients to return to independent productive lives. It also reduces the burden on health and other services, particularly by reducing the number of hospital admissions for and the cost of treating complications such as cellulitis and reducing the needs on the community services and practice nurses.

Many patients are suffering unnecessary due to a lack of lymphoedema services being available in their area. A relatively small amount of money would enable Wales to have an equitable lymphoedema service for all. The Welsh Assembly Government has to carefully consider the implications of not funding lymphoedema provision.
Appendix A - Acknowledgements

The Welsh Assembly Government would like to thank all key stakeholders that have contributed in the development of these lymphoedema recommendations. Special thanks are made to Melanie Lewis and Eilish Lund for their commitment to this publication.
Appendix B - References


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Appendix C - Glossary

**Cellulitis**: A sudden, non-contagious infection of the skin, characterised by redness, swelling and heat, accompanied by pain and tenderness

**Chylous Reflux**: A reflux of intestinal lymph, which is white in colour, on to the skin in the form of a fistula or white vesicles which leak when damaged.

**Decongestive Lymphoedema Therapy**: Consists of a daily treatment programmes which may include MLD/SLD, MLLB, skin care and exercise

**Filariasis**: Lymphatic filariasis is caused by parasitic tissue-dwelling filarial nematode worms which are endemic to the tropics

**Hyperkeratosis**: A build up of horny scales on the surface of the skin

**Klippel-Trenaunay Syndrome**: Characterised by hypertrophy of all tissues including the bones, varicose veins arterovenous fistulas and insufficiency of the lymphatics

**Manual Lymphatic Drainage**: (MLD) is a gentle type of skin massage carried out by trained therapists. The aim is to enhance the removal of proteins from tissues and increase lymphatic flow.

**Multi Layer Lymphoedema Bandaging**: (MLLB) A layer of stockinette followed by various types of soft padding and foam with short stretch bandages applied evenly over the top to give a semi-rigid support to the limb

**Lymphadenitis**: An inflammatory condition of the lymph nodes

**Lymphangiomata**: Consists of extremely dilated lymphatic vessels in the skin which bulges on to the surface giving the appearance of a blister, some forming a tumour-like mass. They may burst and leak fluid or over time change to form thick skin nodules

**Noonan Syndrome**: A multiple congenital anomaly syndrome, caused by a mutation in a single gene. Characteristics include short stature, neck webbing and congenital cardiac anomalies Lymphoedema is usually present at birth but the age of onset may vary

**Milroys Disease**: Known as hereditary lymphoedema type 1. Usually present at birth or before puberty. It comprises swelling of the legs and may involve the genitalia, arms and face

**Pappilomatosis**: Cobblestone-like projections of the skin surface indicating dilated skin lymphatics surrounded by fibroed tissue

**Perometry**: Electronically gathered data that is used to calculate limb volume.

**Sarcoidosis**: A multi system disorder of unknown origin characterised the appearance of granulomas in the lungs or the lymph nodes.
Sarcoma: A malignant growth of the soft tissues

Sentinel Node Biopsy: Used in breast cancer surgery to determine the extent or stage of cancer, because it involves the removal of fewer lymph nodes than the standard procedure the potential for side effects such as lymphoedema is lower

Simple Lymph Drainage: SLD is based on the principles of MLD and is applied by the patient themselves their carer or by the therapist and is used daily as part of a lymphoedema treatment programme.

Turners Syndrome: A congenital chromosomal abnormality found only in women characterised by webbed neck dwarfism, retarded maturation of the skeleton, congenital heart disease and lymphoedema