



Lymphoedema and Lipoedema Treatment in Ireland

**A Model of Care for Ireland – A Working Group
Report**

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Building a
Better Health
Service



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FOREWORD

I am pleased to present the publication of this significant report on 'The development of a Model of Care for the treatment of Lymphoedema and Lipoedema in Ireland'.

Lymphoedema is a progressive, chronic disease that causes swelling of body tissue due to failure in the lymphatic system and can affect people of all ages. It can be congenital or can develop secondary to lymphatic damage due to cancer or its treatment, vascular disease, dependency, trauma or chronic infection. We can estimate that approximately 12,500 people in Ireland suffer from this chronic condition. Lymphoedema is incurable, lifelong and has a significant impact on the quality of life of patients and their family. Specialist lymphoedema services can help to prevent and manage oedema, improve functioning and quality of life and stop the development of infections needing antibiotics and hospitalisation.

This report proposes a model of care for an integrated lymphoedema and lipoedema treatment service involving specialist and non-specialist care being provided in a community setting with links into acute services. It has been formulated based on a review of current international best practice and projected population needs based on current prevalence data and information gathered from a national survey to identify gaps in services. The report sets out the four key elements and recommendations to provide a comprehensive lymphoedema service: Prevention and Early Detection, Assessment, Treatment and Support Services, Education and Research.

We know that the need for lymphoedema services will continue to rise due to an ageing population, increase in obesity and increased cancer diagnosis and survival. Education in early detection and the comprehensive treatment of lymphoedema will provide a way to cope with this demand and help to improve outcomes for patients.

I trust that the report, which provides a blueprint for the development of a comprehensive lymphoedema service and which will make a substantial difference to the quality of life of many patients, will receive the support and resources required to implement it.

It is an early step towards achieving tangible benefits for patients, enhancing recognition and diagnosis of the condition by professionals and the public, improving access to best practice management and providing scope for future development of lymphoedema and lipoedema services in Ireland.

I would like to acknowledge and thank the Working Group for their work, expertise and contributions to the report. A particular thanks to Kay Morris, Project Manager, and to Teresa Cannon for their relentless work, commitment and energy in getting the report to finalisation. I would also like to thank Lymphoedema Ireland for their support and assistance with the report.

It has been a privilege to work with the Working Group members and other professionals and patients to develop and complete this report.

Brian Murphy
Assistant National Director
Strategic Planning & Transformation

Vision for the Future Management of Lymphoedema/Lipoedema

A comprehensive evidence-based range of accessible lymphoedema/lipoedema services of the highest standards including:

- Prevention and early detection;
- Treatment and support;
- Education and research.

The services will be provided by an integrated model of care that enables:

- Equal access,
- Timely assessment,
- Appropriate treatment in the right setting by appropriately trained staff skilled in this specialist service.

LIST OF ABBREVIATIONS

BLS	British Lymphology Society
BMI	Body Mass Index
CBD	Cross Border Directive
CDT	Complete Decongestive Therapy
CHO	Community Healthcare Organisation
CREST	Clinical Resource Efficiency Support Team (Northern Ireland)
DCU	Dublin City University
DLT	Decongestive Lymphatic Treatment
HCP	Healthcare Professional
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
HSCP	Health and Social Care Professionals
HG	Hospital Group
ILF	International Lymphoedema Framework
KPI	Key Performance Indicator
LEBS	Lymphoedema Education Benchmark Statements
LNNI	Lymphoedema Network Northern Ireland
LOS	Length of Stay
LLWG	Lymphoedema/Lipoedema Working Group
MDT	Multidisciplinary Team
MEP	Medical Education Partnership (Authors of International Consensus: Best Practice in the Management of Lymphoedema)
MLD	Manual Lymphatic Drainage or Manual Lymph Drainage
MLLB	Multi-Layer Lymphoedema Bandaging
NLP	National Lymphoedema Partnership
NCEC	National Clinical Effectiveness Committee
NICE	National Institute for Health and Care Excellence
NHS	National Health Service (UK)
PHN	Public Health Nurse
QOL	Quality of Life
SLD	Simple Lymphatic Drainage
SLNB	Sentinel Lymph Node Biopsy
SLC	Specialist Lymphoedema Clinic
TAS	Treatment Abroad Scheme
WHO	World Health Organisation
WTE	Whole time equivalent

EXECUTIVE SUMMARY

The Lymphoedema/Lipoedema Working Group was established in 2016 with the aim of developing a national integrated model of care for the prevention, assessment, and treatment of lymphoedema/ lipoedema in accordance with evidence-based practice.

Lymphoedema and lipoedema are two distinct conditions but the treatment is similar, all lymphoedema services referred to in this Model of Care are inclusive of lipoedema.

Lymphoedema can affect people from birth as a hereditary disease or can develop secondary to other conditions e.g. cancer, vascular conditions, cellulitis.

Lymphoedema and lipoedema are common but under-recognised conditions.

The exact number of patients affected in Ireland is difficult to establish due to under-diagnosis, inaccurate recording and inadequate data collection on the conditions and services provided in both hospital and community. It is estimated that it affects up to 12,380 patients in Ireland and lipoedema is estimated to affect 1 in 72,000 people approximately 66 patients.

Due to the varied aetiology of lymphoedema it is seen by many different health care professions but is often not diagnosed and treatment not understood. Lymphoedema/lipoedema is progressive if not treated and can lead to an increase in secondary problems of pain, cellulitis, hospitalisation, reduced mobility and reduced quality of life including having to give up work.

In Ireland an estimated 1,451 patients a year are admitted to hospital with cellulitis related to lymphoedema with an average length of stay of 11 days, costing approximately €13.6M. Based on international studies this €13.6M cost of treating these patients could be reduced by over 87% if comprehensive lymphoedema services were introduced. This could reduce cost by approximately €11.8M in reduced hospital admissions. The estimated annual cost for services is €5.2M which would give a net saving of €6.6M for reduced admissions alone. There is also a potential to save money by introducing lymphoedema management into the treatment of leg ulcers with chronic oedema which, based on international research, could save up to €7.2M in PHN visits and dressings. These cost savings would be apparent as services are developed and are demonstrable and sustainable.

Lymphoedema is a chronic disease and treatment should be targeted to prevention and early detection with a focus on empowering patients to self-manage their condition. Specialist and non-specialist services are needed with an emphasis on prevention, early detection and self-management.

A 2016/17 survey of current lymphoedema/ lipoedema services showed that;

- Service provision for lymphoedema/ lipoedema is inadequate in most parts of Ireland with significant gaps across the country and inequity of access for non-oncology related lymphoedema.
- There is inconsistency in the prescribing and provision of compression garments which are an essential part of lymphoedema/lipoedema management.
- There is under-utilisation of the current 70 (equivalent to 11.1 WTEs) specialist staff with each working an average of 6 hours per week in lymphoedema services.
- There are long waiting times of up to two years in some areas and patients with non-oncology related lymphoedema have significantly longer waiting times than oncology related.
- There are no consistent treatment standards being used across the country and there are poor identification systems for high risk patients.
- The Treatment Abroad Scheme (TAS), the Cross Border Directive (CBD) and contracted private therapists are currently used which is costly and not sustainable.

- There is very limited lymphoedema/lipoedema education in healthcare-related undergraduate courses.
- Funding for lymphoedema services is not consistent and varies according to health care professional and site of services.
- A gap analysis conducted as part of this review demonstrated a lack of accordance with international best practice in many areas of lymphoedema/lipoedema management.

Model of Care

The proposed 'hub' and 'spoke' model of care will ensure that non-complex lymphoedema/lipoedema cases are maintained in the community with an emphasis on self-care and support. Complex patients will be seen by lymphoedema therapists in a Specialist Lymphoedema Clinic based in primary care with in-reach to appropriate acute services. The SLC will provide assessment, intensive and modified intensive treatment with pathways to a multi-disciplinary team.

Implementing the Model of Care will ensure that the services are safe, equitable, timely, evidence based and consistent with monitored outcomes and a quality improvement focus.

A dedicated funding stream for lymphoedema/lipoedema services will ensure sustainability.

Using calculated service demand there is a need for 56.2 WTEs nationally to provide a comprehensive service. Based on the current WTEs (11.1) allocated time to lymphoedema/lipoedema services this would involve the recruitment of 45.1 additional staff. Many existing expertly trained staff could be appointed to these positions with their non-lymphoedema work carried out by other recruited professionals. There will also be a need for a multitask attendant in each SLC, 9 WTEs in total.

The cost of implementing the MOC is approximately €5.2M with potential demonstrable savings of €19.1M due to reduced hospital admissions, reduced costs in dressings, bandages and use of antibiotics and reduced PHN visits. This would equate to a net annual saving of €13.9M to the Irish health service and a quality service for patients once services were fully established.

There are also savings due to prevention and early detection that are difficult to quantify. Early detection and prevention play an important part in reducing the disease burden in these conditions for which prevalence is expected to increase due to ageing population, increase cancer incidence, cancer survivorship and obesity.

Increased education will ensure that patients are diagnosed early and referred for treatment to limit disease progression and reduce the need for time consuming and costly intense treatment.

Although lymphoedema is not curable, it can be successfully managed with an emphasis on education, awareness, prevention, early detection and up to date effective consistent treatment which will lead to improved outcomes for patients and value for money for the HSE.

1. Background and aims of the Lymphoedema/Lipoedema Working Group

1.1. Lymphoedema/Lipoedema Working Group

A multi-disciplinary cross divisional Lymphoedema/Lipoedema Working Group (LLWG) was established in January 2016 comprising representatives from Primary Care Division, Acute Hospitals Division, Clinical Strategy and Programmes and the National Cancer Control Programme to develop a Model of Care for Lymphoedema/Lipoedema treatment services in accordance with the Primary Care Division Operational Plan 2016. Members of the Working Group were:

- Mr. Brian Murphy, Head of Planning, Performance & Programme Management, Primary Care Division (Chair).

- Dr. David Hanlon, National Clinical Advisor, Primary Care Division.
- Dr. Colm Henry, National Clinical Advisor, Acute Hospital Division (represented by Elaine Brown, Project Manager, Acute Hospital Division).
- Dr. Mary Paula Colgan, Associate Professor of Vascular Disease, St. James's Hospital and TCD.
- Dr. Marie Laffoy, National Cancer Control Programme.
- Ms. Emma Benton, Programme Manager, Office of National Clinical Advisor, Primary Care (until December 2016).
- Ms. Helena Maguire, Primary Care Specialist, Office of Head of Planning, Performance & Programme Management.
- Ms. Hilary Murphy, Nurse Specialist, National Cancer Control Programme.
- Ms. Kay Morris, Project Manager (joined, September 2016).
- Ms. Fiona McNamara, Portfolio Management Lead (until September 2017).

1.2. Aim

The aim of the Working Group was to develop a Model of Care for Lymphoedema/Lipoedema Treatment, based on best practice and fit for purpose for the Irish health services.

The purpose of this Model of Care is to support:

- Prevention of lymphoedema/lipoedema occurring where possible.
- Early detection of lymphoedema/lipoedema.
- Comprehensive, safe and consistent management of the conditions.
- Achievement of optimal patient outcomes and quality of life.

1.3. Objectives

- Improve access to services.
- Provide safe, high quality health care.
- Promote a patient centred continuum of care.
- Reduce inequality in health status.
- Improve the balance of preventative, primary and acute care.
- Support a highly skilled and motivated workforce.
- Ensure a value for money approach is adopted.

The Model of Care will inform the development of standards of care and key performance indicators (KPIs) for services in Ireland which should be developed subsequent to the publication of the Model of Care.

The Model of Care was developed using a holistic, system wide approach which included a survey of current services to identify deficiencies, a review of international standards and reports and recommendations from expert groups.

The LLWG recognises that the Model of Care is dynamic and will strive to identify factors that may require revision of the model in the future e.g. new diagnostic techniques and surgical advancements

2. Introduction

2.1. Definition of lymphoedema

Lymphoedema has been recognised as a chronic disease since 1940. It is a chronic, progressive condition resulting from failure of the lymphatic system to drain fluid and proteins from tissue throughout the body and return it to the circulatory system. Lymphoedema is progressive, and if not treated, will become more complex. See **(Figure 1)** below for examples of lymphoedema. There are two main types of lymphoedema:

Primary lymphoedema is caused by abnormal development of the lymphatic system. Symptoms may be present at birth, develop at puberty or in midlife.

Secondary lymphoedema is caused by damage to an otherwise healthy lymphatic system. Secondary lymphoedema includes lymphoedema caused by venous disease, reduced mobility, cellulitis, obesity, trauma and oncology related lymphoedema

When the lymphatic system is compromised the result is swelling, most typically in the limbs **(Figure 1)** but can affect any part of the body including breast, trunk, genitalia and face. Due to the many causes of secondary lymphoedema it can be multi-faceted leading to a complex condition with co-morbidities.

'**Chronic Oedema**' is often used interchangeably with the term 'Lymphoedema' and encompasses all forms of oedema that persists for more than 3 months (Moffatt, 2003). Although the term 'lymphoedema' suggests that the oedema is caused by a lymphatic abnormality, in every case of chronic oedema there will be some impairment of lymphatic drainage as a result of the capacity of the lymphatics being overloaded.

The current services in Ireland distinguish between "oncology related" lymphoedema and "non-oncology related" lymphoedema; these terms will be used to reflect this distinction in the document.

Figure 1: Lymphoedema



2.2. Definition of Lipoedema

Lipoedema is a chronic incurable condition involving a pathological build-up of adipose tissue (Wounds UK, 2017) **(Figure 2)**. It is a common condition, occurring almost exclusively in women. Despite the unknown cause of lipoedema there is evidence of hormonal and hereditary influences. It typically affects the thighs, buttocks and lower legs, and sometimes the arms, and may, although not always, cause considerable tissue enlargement, swelling and pain. It may significantly impair mobility, ability to perform activities of daily living, and have a negative impact on psychosocial wellbeing. While there is no effective cure for lipoedema, a number of therapies are effective in managing symptoms. When lipoedema progresses to lymphoedema it is termed lipolymphoedema which arises from an overload of the lymphatic system, causing oedema.

The differences between lymphoedema, lipoedema and obesity are included in **Appendix 1**

Figure 2: Lipoedema



Reproduced with permission from Wounds UK 2017.

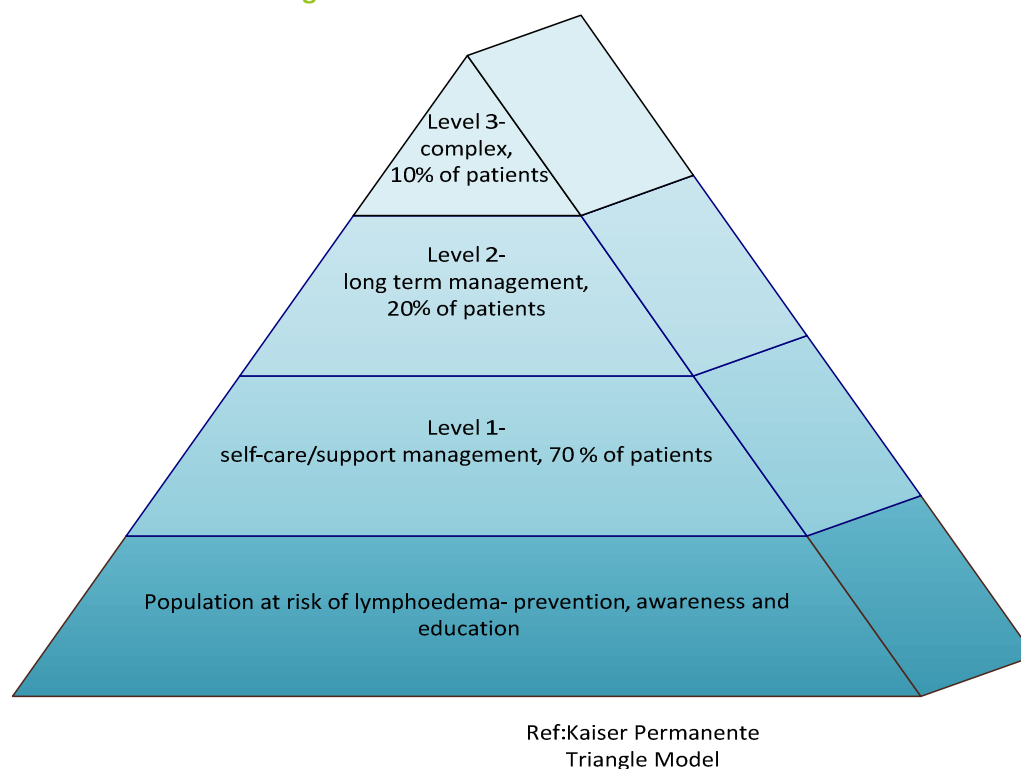
2.3. Lymphoedema and Lipoedema as chronic diseases

Lymphoedema and Lipoedema are chronic conditions which can be effectively treated but not cured, they meet the key features of chronic illnesses:

- Have complex and multiple causes.
- Usually have a gradual onset.
- Occur across the life cycle, being more common with older age.
- Can cluster in individuals by virtue of age, common risk factors, and possible common systemic responses.
- Compromise quality of life through physical limitations and disability.
- Are long-term persistent, leading to deterioration in quality of life.
- Costly in terms of service provision.
- Perpetuate health inequalities significantly.

Chronic disease may be categorised into four levels that relate condition severity with accompanying proportion of patients to level of intervention required (**Figure 3**). The four levels are consistent with the management and treatment of lymphoedema/lipoedema.

Figure 3: Chronic Condition Management Model



As with all chronic diseases it is essential that lymphoedema/lipoedema are prevented where possible, detected and treated early. The population at risk, the largest proportion of the management triangle, depicted in **(Figure 3)** need to be actively targeted through awareness, education and prevention programmes. Lymphoedema and lipoedema can be maintained and controlled effectively, improving quality of life for patients and reducing costs due to appropriate intervention at the right time, thereby reducing the requirement for more intensive and expensive treatment. If untreated lymphoedema/lipoedema is progressive and can lead to an increase in secondary problems of pain, cellulitis, hospitalisation, reduced mobility and reduced quality of life including early retirement from work (BLS 2013). In a study of 228 lymphoedema patients, **80%** had to take time off work and **8%** had to give up work completely (Moffatt, 2003). The physical, emotional and economic impact of the condition is enormous and much can be achieved to mitigate these impacts.

2.4. Prevalence of Lymphoedema and Lipoedema

Unfortunately, the prevalence of lymphoedema or lipoedema in Ireland is not known as there is no accurate data available. Given the nature of these conditions it is reasonable to estimate prevalence based on comparative data in other jurisdictions.

2.4.1. Prevalence of lymphoedema

The accuracy of prevalence of lymphoedema is evolving internationally as different rates have been recorded over the last two decades with more recent studies arriving at agreed prevalence rates within closer parameters. In 2003 Moffatt et al, completed a study in the UK and suggested that **1.33** per 1,000 people of all ages are affected with lymphoedema, with this increasing to **5.4** after the age of 65. This was thought to be an underestimation at the time and more recent studies (Moffatt and Pinnington, 2012) showed a rate of **3.99 per 1,000** across all ages. In Northern Ireland the latest data recorded is **4.83 per 1,000**. Primary lymphoedema is estimated to be 1 in 6,000 births (Dale, 1985).

More recent data from the All Wales Lymphoedema Operational Framework 2016, indicated a rate of **2.6 to 5.49 per 1,000**. This was based on referral data over the previous 5 years. In a 2017 study a rate of **3.93 per 1,000** was recorded for chronic oedema (Moffatt 2017). The term chronic oedema was used instead of lymphoedema to encompass all forms of oedema over 3 months duration irrespective of aetiology.

Having taken into account these and other studies and consulted with experts, the Working Group determined that using a conservative rate of **2.6 per 1,000** as a baseline for Ireland was reasonable and prudent to use. This decision was made in the absence of accurate Irish data and in the expectation that an accurate data recording system will be developed. As services develop and a data recording system is implemented it is reasonable to expect that this prevalence figure of **2.6 per 1,000** will change.

Using the prevalence rate of **2.6 per 1,000** people and the current population of 4,761,865 (Central Statistics Office, 2016) in Ireland, it can be estimated that there are approximately **12,380** lymphoedema patients in Ireland.

Table 1: Estimated overall prevalence of primary and secondary lymphoedema

Population in Ireland	Prevalence rates		
	1.3 in 1,000 5.4 in 1,000 (>65) (Moffatt, 2003)	2.6 in 1,000 (Wales, 2016)	3.99 in 1,000 (Moffatt, 2012)
	Estimated Number of lymphoedema patients		
Total- 4,761,865	6,190	12,380	19,000
Age Related			
<65- 3,857,110 (81%)	5,014		
>65- 904,755 (19%)	3,443		
Total	8,457		

It is well documented that the prevalence of lymphoedema increases with age due to immobility, venous insufficiency and other co-morbidities (Moffatt, 2003; Sneddon, 2008; Moffatt, 2012).

From studies conducted in Wales and Northern Ireland the ratio of cancer to non-cancer lymphoedema is approx. 50:50 and 48:52 respectively in their services. We can deduce from this data that the Irish data would not be significantly different.

When comparing the data recorded in the HSE acute services HIPE system to the expected data there appears to be hugely significant under-diagnosing/under reporting of lymphoedema **Table 2**. There is no HIPE data available for lipoedema as the disease does not have a code in the HIPE system and it falls under the general oedema code.

Table 2: HIPE data for No. of patients coded for lymphoedema 2014-2016

Discharge year	No. of discharges with a diagnosis of lymphoedema	No. of discharges with an additional diagnosis of lymphoedema
2014	89	284
2015	63	324
2016	82	314

This data includes the following ICD-10-AM diagnosis codes:

I89.0 Lymphoedema, not elsewhere classified

Q82.0 Hereditary lymphoedema

I97.2 Post mastectomy lymphoedema syndrome

2.4.2. Prevalence of Primary Lymphoedema

It is estimated that **10%** of the total number of lymphoedema patients have primary lymphoedema which can be congenital and present at birth, or may develop later in life (praecox from ages 1-35 and tarda after 35 years). This would give an estimated 1,238 patients in Ireland with primary lymphoedema.

2.4.3. Prevalence of Oncology related Lymphoedema

Lymphoedema is a recognised complication related to cancer treatments e.g. lymph node removal, and/or radiation therapy. It can also be caused by the tumour itself obstructing the lymphatic system. The prevalence is variable depending on the cancer location and stage of disease. The estimated prevalence, the number of new patients diagnosed per year and the estimated number of potential patients affected by lymphoedema per year is summarised in **Table 3**. Sentinel Lymph Node Biopsy (SLNB) has reduced the risk of developing lymphoedema but a large cohort study of breast cancer patients has concluded that risk is also related to the multimodal treatments; chemotherapy and radiation, weight and disease stage, and not surgery alone and there is still a **5.3%** risk of developing lymphoedema following an SLNB (Nguyn, 2017).

Table 3: Estimates of oncology related lymphoedema

Malignancy	Prevalence	Number of new cases per year	Estimated No of new lymphoedema patients
Breast	12-25%	2919	350-729 Median 539
Gynaecological	33%	1076	355
Melanoma	20%	968	194
Prostate	10%	3364	336
Bladder	10-20%	438	44-88 Median 66
Total		8765	1490

2.4.4. Non-Oncology Related Secondary Lymphoedema

Non-oncology related secondary lymphoedema can be related to:

- I. Venous insufficiency
- II. Cellulitis
- III. Dependency
- IV. Obesity
- V. Palliative

I. Prevalence of venous insufficiency related lymphoedema

Venous insufficiency and ulceration are linked with impaired lymphatic flow and a study in 2004 showed that **42%** of patients with leg ulceration also had lymphoedema (Moffatt, 2004). The prevalence of leg ulcers has been estimated at **0.45** per 1,000 and women are twice more likely to be affected than men (Moffatt, 2004). In a study undertaken in the year 2000 in Ireland leg ulcers were prevalent at a rate of **0.12%** in the general population of <70 years and **1.03%** in the general population of >70 years (O'Brien, 2000). A more recent study by Moffatt et al showed a chronic oedema prevalence of 3.39 per 1000 (Moffatt, 2017) which would equate to 16,143 patients in Ireland and estimating that **40 %** (Moffatt, 2017) of patients with chronic oedema had concurrent leg ulcers would indicate 6,457 patients in Ireland.

II. Prevalence of cellulitis and lymphoedema

Cellulitis is a complication of lymphoedema but can also be a cause. Recurrent cellulitis is thought to lead to lymphoedema due to a chronic cycle of infection causing prolonged swelling and subsequent damage to the lymphatics (Keeley, 2008).

In a study of patients admitted to acute services for cellulitis, lymphoedema was a major factor for **18%** (Moffatt, 2016).

HIPE data from 2014 to 2016 demonstrates a yearly increase in the admissions for cellulitis **Table 4**. Data in 2016 showed just over 8,000 admissions for cellulitis. Using the **18%** rate (Moffatt 2016) of hospitalised patients having lymphoedema as a major factor it can be estimated that 1,451 of these patients could have significant lymphoedema and a high risk of re-occurrence. The 2015/2016 HIPE data showed an average LOS of 11 days for major complexity cellulitis which would corroborate the research data of 10-12 days for cellulitis patients with lymphoedema. **This would equate to a cost of approximately €13.6m for hospital admissions with cellulitis related to lymphoedema/chronic oedema.**

Table 4: HIPE Data for cellulitis 2014 and 2016

Discharge year	No. of discharges with a principal diagnosis of cellulitis	No. of Discharges with an additional diagnosis of cellulitis	Potential patients with cellulitis related to lymphoedema (18%)	Potential costs (average LOS x cost per night) 11 x €856
2014	6,030	5,100	1,091	€10,272,856
2015	7,571*	N/A	1,363	€12,834,008
2016	8,063*	N/A	1,451	€13,662,616

*2015/2016 HIPE data used DRG levels and cellulitis was grouped as major or minor complexity. For comparison reasons these figures are combined in this data.

III. Dependency related lymphoedema

Individuals who rely on wheelchairs for mobility are at higher risk for chronic swelling due to limited or absent calf-pump function and the negative effects of sitting for long periods of time such as limb dependency and impeded venous and lymphatic flow (Cavorsi, 2000). A study in America demonstrated a **9.2%** incidence of lymphoedema in adults with spina bifida (Garcia, 2011) noting this was 100 times more than the general population in America. Spina bifida affects approximately 1 in every 1,000 children born per year in Ireland. There are an estimated 2,500 people with spina bifida in Ireland (Spina Bifida Hydrocephalus Ireland) which indicates that there are approximately 230 people with spina bifida in Ireland with chronic oedema/lymphoedema.

IV. Obesity related lymphoedema

Obesity leads to an increase in the incidence of lymphoedema and it is also a poor prognostic factor in treatment outcomes (Soran, 2011). The increase in the girth of the abdomen causes pressure on the inguinal vasculature and reduces lymphatic and venous return. Adult obesity is increasing; according to the World Health Organisation (WHO) by 2030 **57%** of women and **48%** of men are projected to be obese. One established lymphoedema service in England has reported that **63%** of their patients have a Body Mass Index (BMI)>30 and **21%** have a BMI >40.

An oncology study for breast cancer patients demonstrated that patients who put on weight following treatment are at an increased risk of developing upper body lymphoedema (Birmingham, 2006).

V. Palliative care lymphoedema

The incidence of lymphoedema/oedema at end of life has been estimated to be between **5-10%** of referred palliative patients (North London Cancer Network, 2006/2010, **12%** (Potter, 2003) and a study in Ireland in the Milford Care Centre (Real, 2015) found an incidence of **10.5%**.

The total number of palliative patients in Ireland is not currently available as the data is linked to service rather than the individual and patients can access many palliative services. There were 3,019 patients admitted to

hospice settings in 2016 which would equate to approximately 300 palliative patients with lymphoedema in a hospice setting each year in Ireland.

2.4.5. Prevalence of Lipoedema

In England it was estimated that the incidence of lipoedema is **1 in 72,000** (Child, 2010), this was accepted to be a low estimation. In Germany it was estimated to be **11%** of women and post-pubertal girls (Földi et al, 2006; Szél et al, 2014). In Ireland this would equate to approximately 260,000 women having lipoedema. Studies have also indicated that positive family history in patients is a factor. These studies' findings ranged from prevalence of family history being a factor of between **16% to 64%**. Due to the large discrepancy in these numbers it is evident that diagnosing and data collection is poor and reliable data in Ireland will be achieved by improved awareness, education and systematic data collection.

Prevalence Key points

- There are an estimated 12,380 people with lymphoedema in Ireland.
- There are an estimated 1,451 admissions a year to acute hospitals for cellulitis related to lymphoedema/chronic oedema, costing approximately €13.6m a year.
- There are an estimated 1,238 patients with primary lymphoedema in Ireland.
- There are an estimated 1,490 new patients per year diagnosed with cancer related lymphoedema.
- There are an estimated 300 patients referred to specialist hospice palliative care services per year that have a complication of oedema.
- **50%** of lymphoedema patients are non-oncology related.
- Prevalence will increase due to ageing, cancer survival and increasing obesity.
- There is a lack of diagnosis and accurate data collection thereby making it difficult to estimate the true prevalence of lymphoedema and lipoedema in Ireland.

2.5. Treatment for Lymphoedema/Lipoedema

The standards for lymphoedema treatment are recognised internationally and in 2006 the International Lymphoedema Framework produced the Best Practice for the Management of Lymphoedema and in 2008 the Clinical Efficiency Support Team (CREST) developed guidelines on the Diagnosis, Assessment and Management of Lymphoedema through the Northern Ireland Cancer Network. For lipoedema the Best Practice Guidelines for Lipoedema were published in 2017 (Wounds UK, 2017). Due to the similarity in treatment of lipoedema and lymphoedema it was concluded that lipoedema patients are best treated in a lymphoedema service. Accordingly, for ease of reading all references to lymphoedema in this document are inclusive of lipoedema services.

Effective treatment by therapists can produce significant objective changes in limb size, improve quality of life, minimise complications and reduce pain (**Figure 4**). Prevention and early detection of lymphoedema and lipoedema can reduce incidence and control symptoms. Once the symptoms are stable self-management with regular review is essential for health and economic benefits. (Note: the term “therapist” is used to reflect all lymphoedema therapists including Health and Social Care Professionals (HSCP) and Nurses).

Figure 4: Upper limb lymphoedema and lower limb lymphoedema before and after treatment.



Images reproduced with permission from Klose Training.

The aims of treatment are to:

- Educate in the understanding of the condition and the rationale for treatment.
- Maximise lymphatic drainage and minimise fibrosis.
- Improve limb shape.
- Restore functional activity and improve quality of life.
- Promote self-care and independence.
- Reduce the risk of infection and exacerbation.
- Provide long term control of oedema.
- Reduce unnecessary hospital admissions.

2.5.1. Lymphoedema Treatment:

Level 1 Prevention and reducing risk

Education should be provided for all high risk patients. Clinicians need to be aware of the risk factors and understand the measures to reduce the risk. Also, education for patients is necessary to improve their detection of early signs of lymphoedema and to help them seek immediate treatment.

Level 2 Intensive treatment

There are four elements of intensive treatment:

- **Exercise:**
Exercise can help to improve lymph flow and reduce oedema. A combination of flexibility, resistance and aerobic exercise is recommended and should be tailored to individual patients. Normal function and mobility should be encouraged.
- **Skin care:**
Maintenance of skin integrity and careful management of skin problems are important to reduce the risk of infection. The principle of skin care is to preserve the skin barrier function through regular washing and the use of emollients.
- **Manual Lymphatic Drainage (MLD):**
MLD is a gentle massage technique that encourages the movement of fluid away from congested areas by increasing activity of normal lymphatics and by-passing ineffective lymph vessels.
- **Compression:**
Compression can be in the form of multi-layered lymphoedema bandages (MLLB) and/or compression wraps for reducing oedema. The use of Velcro wraps allow for 'supervised self-management' of lymphoedema and Velcro wraps are easier for patients to manage. This allows appropriate patients more control over their compression which adds to their involvement in their care (Wigg, 2009a).

The combination of exercise, skin care, MLLB and MLD is collectively called Complete Decongestive Therapy (CDT) or Decongestive Lymphatic Therapy (DLT). The term intensive treatment is used in this document to include a holistic approach including CDT, psychosocial care, pain management, weight management and any treatment required that is identified on assessment. Intensive treatment requires a significant commitment from the patient and therapist and a patient centred approach, with the patient directly involved in the planning of their treatment, is essential to ensure adherence and improve outcomes. Intensive treatment should be available daily for MLD and bandaging and will usually require at least 60-90 minutes per session.

Level 3 Modified Intensive treatment

Modified intensive treatment includes all the elements of the intensive regime but tailored to a patient's needs. This would be appropriate in palliative patients, frail patients and patients with co-morbidities or patients that cannot commit to full intensive treatment.

Level 4 Maintenance treatment

Once the symptoms are controlled long term maintenance treatment will begin with regular reviews, measurement for new compression garments at least every 6 months and support provided with a focus on self-management. One visit to a therapist every 6 months is required which will take 30 minutes per session. Compression garments, as detailed previously, are an essential part of lymphoedema treatment and are used to maintain improvements after intensive treatment and also as a preventative measure. Garments may be either 'off the shelf' or custom-made depending on the patient's presentation. They are a significant cost for patients who do not have a medical card. In some CHO areas the annual allowance for garments for medical card patients is below the best practice recommendations of two garments every 6 months. The cost of compression garments was identified as a barrier to treatment in the DCU study (Murray, 2010). This view was re-enforced in the stakeholder engagement process undertaken by the Working Group. Correct prescribing of garments is essential to ensure patient safety, best patient outcomes, compliance and value for money.

Prevention and reducing risk and maintenance treatment can be effectively provided by the generalist clinicians who do not require demanding levels of training. Intensive treatment and modified intensive treatment need to be provided by Lymphoedema Therapists who have undergone an ILF recognised course in lymphoedema management.

Algorithms for treatment choices are available in the International Lymphoedema Framework (ILF) consensus document, 2006 and in the UK Best Practice guidelines for Lipoedema. The ILF is an International collaboration to improve the management of lymphoedema and related disorders worldwide. The ILF published consensus documents are recognised internationally as best practice and were an essential source of reference in the development of this Model of Care.

There are other treatments available for lymphoedema e.g. intermittent pneumatic compression, laser and surgery and up to date research on these should be reviewed as part of the Model of Care implementation process for possible incorporation into the future services.

2.5.2. Clinical Severity Groups and appropriate treatment levels:

The level of treatment required depends on the severity of the condition. The British Lymphology Society (BLS, 2001) recognises 4 clinical groups of severity:

Clinical Group 1- Sub-clinical or pre-lymphoedema. Typically includes all patients who have had lymph node dissection. Swelling is not evident, despite impaired lymph flow.

Clinical Group 2- Patients with mild and uncomplicated oedema

Clinical Group 3- Patients with moderate to severe oedema

Clinical Group 4- Patients with severe oedema and advanced malignancy.

Treatment is provided to patients, based on the severity of their condition, in accordance with the four defined clinical group classifications. As explained in 2.5.1 treatment is divided into four treatment levels:

- Prevention
- Maintenance/self-care support
- Modified intensive
- Intensive

Table 5 sets out the appropriate treatment levels and the related summary treatment details for each of the 4 clinical groups.

Table 5: Treatment according to Clinical Group

Lymphoedema Group	Clinical Group 1 Sub clinical	Clinical Group 2 Mild	Clinical Group 3 Mild/Moderate	Clinical Group 4
Treatment Level	Prevention	Maintenance/Self-care/Support	Modified intensive treatment	Intensive treatment
Treatment Details	<ul style="list-style-type: none"> • Screening for high risk patients. • Education in awareness and prevention. 	<ul style="list-style-type: none"> • Compression garment • Skin care • Exercise • Review at least every 6 months • Psychosocial support • Education 	<ul style="list-style-type: none"> • Compression garments • Skin care • Exercise • MLD if appropriate • MLLB if appropriate • Education 	<ul style="list-style-type: none"> • Compression garments • Skin care • Exercise • MLD • MLLB • Education

As clinical group 1 is concerned with the preventative aspects of lymphoedema/lipoedema across all disciplines and high risk groups it is not possible to accurately predict estimated hours. However, similar to other prevention strategies it would need to form part of the relevant education programmes and care pathways. The table below sets out the estimated time for treatment by clinical groups 2, 3 and 4. This suggested treatment time is consistent with the recommendations of the BLS tariff document.

Table 6: Estimated time for treatment by each Clinical Severity Group:

Treatment timeframe	Clinical Group 2 Mild (hours p. a)	Clinical Group 3 Mild/Moderate (Hours p. a.)	Clinical Group 4 Moderate/Severe (hour's p.a.)
First year	2	20	60
Second year and subsequent years	1	6	6

(Adapted from the LNNI capacity and demand review 2014)

Using the proportions from the chronic conditions model of care, designed by Kaiser Permanente, at set out in **(Figure 3)**, the proportion of patients requiring the different levels of treatment can be deduced as follows:

- **70%** of patients, once stabilised, will require 6 monthly reviews and can self-manage with support. Non-specialist services are needed for this level of treatment.
- **20%** of patients are long term management and will require maintenance treatment and possibly intensive treatment. Specialist services are needed for this level of treatment.
- **10%** of patients are complex and will always require maintenance treatment and regular intensive treatment to prevent oedema worsening. Specialist services are needed for this level of treatment.

Lymphoedema/lipoedema can deteriorate depending on a number of factors e.g. hot weather, infection, immobility. Such deterioration will require intensive treatment until the oedema is stabilised again. It is, therefore, important that patients have timely access to a lymphoedema/lipoedema clinic for intensive treatment to prevent deterioration of their condition.

Lymphoedema treatment for palliative patients

The needs of patients with lymphoedema in advanced disease and who require palliative care are complex. The aim of treatment is to provide relief from symptoms such as pain and heaviness in the affected limb. Patients who develop end of life oedema may or may not have lymphatic failure but symptoms can develop quickly and cause considerable distress. Implementing the appropriate levels of lymphoedema treatment are crucial to minimise discomfort and prevent further complications.

Psychosocial support

Psychosocial support is very important in chronic disease management and can have a positive impact on outcomes, including self-management and improving quality of life. In a literature review (Fu, 2013) it was concluded that lymphoedema had a negative impact on psychosocial wellbeing. Patients should be empowered and encouraged to share experiences, information and ideas and to have support locally. Local therapists should be working with support groups where possible and encouraging family members and friends to engage in psycho-educational programmes to train them in lymphoedema management techniques. This would encourage them to support their loved ones, thereby improving patients' adherence to their management plan and increasing the level of involved, informed social support patients receive (Person et al., 2008). This would also have the benefits of combating feelings of isolation and maximising the use of limited resources.

Treatment Key Points

1. Lymphoedema and lipoedema are chronic diseases where 70% of care should be provided in the primary care setting with non-specialist services and 30% of care should be in specialist centres (community based) for assessment, complex patients and intensive treatment.
2. Patient centred treatment plans are essential. Patients are partners, involved in planning their health care and encouraged to take responsibility for their own health.
3. Early detection and treatment can prevent the condition worsening with fewer requirements for intensive treatment in specialist centres.
4. Although treatment is not a cure it can improve quality of life and prevent complications such as cellulitis which will reduce unnecessary hospital admissions.
5. Treatment for complex patients can require up to 60 hours per year with patients requiring maintenance treatment having 1-2 hours treatment per year.
6. Intensive treatment needs to be provided on a daily basis, as required, to be effective and to achieve optimal outcomes.
7. Correct prescribing of compression garments is essential to ensure best patient outcomes, patient safety, compliance and value for money.
8. Lymphoedema can be a complication for approximately 10% of palliative care patients and providing appropriate treatment can alleviate symptoms and enhance quality of life for patients.
9. Psychosocial support for patients is an essential aspect for the effective treatment of lymphoedema/lipoedema and assists patients with self-management of their condition and promotes better independence.

2.6. Conclusion

Lymphoedema/lipoedema are chronic conditions that cannot be cured but can be treated and managed successfully and allow patients to lead full lives and enjoy positive health benefits. From projected population health data there is going to be an increase in our ageing population, increase in cancer diagnosis and survival, and obesity which will all lead to an increase in the incidence of lymphoedema/lipoedema (Planning for Health, 2017). Current services need to be developed to manage the current need but it is essential to develop prevention, early diagnosis and treatment services to reduce the projected increases.

A reliable prevalence of lymphoedema/lipoedema in Ireland is not available due to non-standardised recording of the conditions. Consequently, the health services does not have a regularly compiled minimum data set. Planning and budgeting for comprehensive lymphoedema/lipoedema services will require comprehensive education for all health professionals that will contribute greatly to early detection, diagnosis and appropriate treatment. Such improved detection, diagnosis and treatment will need to be captured utilising standard clinical code recording of conditions; this will be included in the Model of Care.

3. Current Lymphoedema Services in Ireland

3.1. Introduction

As previously stated, there is a lack of data available on existing lymphoedema services in Ireland. The services are fragmented, non-standardised and lack full-country coverage. They are offered through multiple disciplines; physiotherapy, nursing and occupational therapy. Most existing services have evolved and developed in a reactive rather than planned way, meeting immediate local demands in the absence of national guidance and direction. This has resulted in services with varying structures; some in acute care and others in primary care. In order to assess, document and quantify the existing services it was agreed by the Working Group to undertake a national survey and also review research carried out.

Dublin City University Research

In 2010 DCU, in association with the Irish Cancer Society, published a research paper; *Living with lymphoedema in Ireland: patient and service provider perspectives*. This research is the only information available that relates to the experience of lymphoedema patients in Ireland and a summary of the results is presented here. There were three stages to the study; the first phase was a postal survey of lymphoedema practitioners, the second phase employed focus group methodology to explore patients' experiences of accessing treatment and living with lymphoedema and the third phase involved a postal survey of lymphoedema patients to investigate the experiences of a wider group of lymphoedema patients.

The results of the service provider survey indicated that lymphoedema services are insufficient and inequitably provided and that there are challenges to the sustainability of the existing inadequate services due to the absence of dedicated funding. The survey further found that therapists currently working in lymphoedema/lipoedema services work an average of 8 hours per week on this service with the remainder of their working week dedicated to other workload. Therapists in dedicated services had high rates of competency and confidence compared to therapists working less hours. **94%** of respondents felt that professional development was lacking.

Some of the findings of the patient focus groups included themes of barriers to treatment which included access issues such as travelling long distances - **25%** had to travel more than 50km for treatment. Waiting times were an average of 6 months for oncology related lymphoedema services and 4 years for non-oncology. Compression garments were also a barrier, **70%** did not receive garments every 6 months, **42%** were required to pay for garments and **60%** had a medical card but stated that this caused delays in receiving their garments. Other themes included participants taking an active role in their lymphoedema management and deriving positives out of their experiences.

The patient questionnaires reiterated the inequitable nature of current lymphoedema service provision and further explored the impact of the condition on patients' daily life and quality of life. Patients did not know that they had been at risk of lymphoedema with a range of awareness levels recorded. **52%** of breast cancer patients were aware of the risks, **24%** of other cancer patients and **5%** in non-oncology patients were aware of the risks. Overall non-oncology services were rated the lowest in patient satisfaction, QOL outcomes, waiting times and service provider ratings.

The recommendations from the study were categorised under three headings:

- Service development.
- Raising awareness of lymphoedema and training amongst healthcare professionals.
- Raising awareness of lymphoedema amongst people at risk and patients with lymphoedema.

This research has been very informative in developing this Model of Care and the recommendations of the study are echoed in the recommendations in this document.

Survey by Working Group of current lymphoedema services

As previously stated the Working Group decided, due to lack of available data, to conduct an assessment of existing lymphoedema/lipoedema services in the country. It was determined that the most efficient method was to conduct a survey. The survey was carried out in November 2016 using the online Survey Monkey tool. An initial letter was sent to the CHO's Chief Officers and the Hospital Group Chief Executive Officers requesting a contact / liaison person to inform the Group of current service provision in the respective CHOs/HGs. The liaison people were also requested to provide contact details of known persons who were familiar with the local lymphoedema services, which would be significant sources of information and would be appropriate to complete the survey. There were 24 responses from 43 survey invitees to the on-line survey. There were 2 services identified after the survey results were collated and these were incorporated into the results as appropriate. The 24 responses included 3 from private practitioners, 7 from HSE Primary Care staff, 12 from HSE Acute staff and 2 from Palliative Care facilities part funded by the HSE. A summary of the results were circulated to the CHOs and HGs for verification prior to inclusion in the report.

The lymphoedema palliative care services provided in hospices and through palliative home care teams are presented in **Table 9**. These results were also circulated for verification prior to inclusion in the report.

Undergraduate lymphoedema education review

A preliminary review was carried out via email to all universities providing physiotherapy and occupational therapy undergraduate programmes to establish the level of undergraduate lymphoedema/lipoedema education provided. 7 universities were contacted and 3 universities did not respond. From the responses there were 4 courses having a lymphoedema element in their curriculum, varying from 1 hour to 18 hours (3 physiotherapy and 1 occupational therapy course). Current education curricula for nursing were also reviewed and did not include lymphoedema education as a component.

3.2. Lymphoedema Survey results

The results of the lymphoedema services on-line survey are presented for each CHO area and the associated acute hospital services in the following pages. The results are presented in sections as follows:

- Location of service.
- Type of service provided; oncology related or non-oncology related lymphoedema.
- Level of service; prevention/maintenance/modified intensive and intensive treatment.
- The service provider, number of staff trained to level 3 and the dedicated hours/WTE.
- Compression garment provision.
- Waiting times.
- Referral source.
- Standards of care.
- Access to support services.
- Identification of high risk patients.

Location of services

- There are a total of 26 lymphoedema services in Ireland according to the survey responses received, including 2 services that were recognised after completion of the survey. The location of each service and the type of service is presented in **Table 7**. Of the 26 services, 12 are in primary care and 14 are hospital-based.
- 4 of the 26 services are provided by private practitioners, funded by the HSE.
- 7 of the primary care services are in CHO 1, 2 in CHO 2, 1 in CHO 4, 1 in CHO 5 and 1 in CHO 8.
- CHOs 3, 6, 7 and 9 do not have primary care services.

Table 7: Current lymphoedema services per CHO and associated acute hospitals.

CHO	Number of services	Location of Primary care service	Location of acute hospital service
CHO 1	7 PC 1 Acute	Cavan PC	Sligo University Hospital
		Monaghan PC	
		Donegal PC: 5 network services	
CHO 2	2 PC 1 Acute	Mayo PC	University Hospital Galway
		Roscommon PC	
CHO 3	1 Acute	No lymphoedema service	Limerick (Private service)
CHO 4	1 PC 4 Acute	Private therapist	Cork University Hospital
			Mercy University Hospital
			Kerry University Hospital
			South Infirmiry Victoria University Hospital
CHO 5	1 PC 1 Acute	Private therapist	Waterford University Hospital
CHO 6	1 Acute	No lymphoedema service	St Vincent's Dublin (Private service)
CHO 7	2 Acute	No lymphoedema service	St James's Hospital, Dublin
			St Luke's Dublin (Oncology)
CHO 8	1 PC 1 Acute	Portllington PC	Our Lady of Lourdes, Drogheda
CHO 9	2 Acute	No lymphoedema service	Beaumont Hospital Dublin
			Mater Hospital Dublin
Total	26	12 PC	14 Acute

Oncology
Non-oncology and oncology
Breast care only
Lower limb only

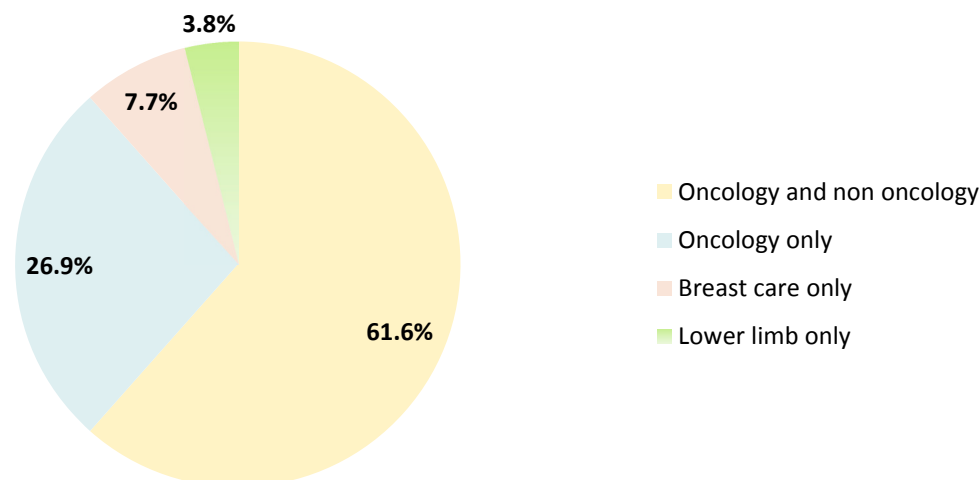
Types of service provided

The types of services provided are categorised as either oncology related lymphoedema and/or non-oncology related lymphoedema. Of the 14 services based in acute hospitals - 5 provide treatment for all oncology related lymphoedema, 2 for breast cancer patients only and 6 provide treatment for both oncology and non-oncology services and 1 provides treatment for non-oncology lower limb lymphoedema only (**Figure 5**).

- Of the 12 primary care services, 2 services provide oncology related treatment only.
- There are no services for non-oncology related lymphoedema in CHOs 3, 6, 7 and 9.
- CHO 6 has services for breast cancer related lymphoedema only.
- Overall, **35%** of services do not provide a service for non-oncology lymphoedema.
- 5 of the 9 (**55%**) of CHOs do not have a lipoedema service; CHO's 2,3,5,6 and 9.

Overall results of the 9 CHOs, including associated HGs, show that there are both oncology and non-oncology services in 5 CHOs, some oncology only services in 3 CHOs and breast care only services in 1 CHO.

Figure 5: Type of service



Although the data shows that there are services in each area this should not be interpreted as a reflection of service adequacy. Most services have a very limited number of hours dedicated to lymphoedema/lipoedema and are providing a wholly inadequate level of service.

Levels of Service

The survey sought to ascertain levels of service under the following categories:

- Prevention/ maintenance only.
- Modified intensive (at least 3 days per week).
- Intensive (daily).

The results showed that:

- 5 services provide maintenance/prevention treatment only services restricted to oncology patients. 3 of the 5 services that provide maintenance treatment have fully trained staff but do not have the resources to provide intensive treatment.
- 3 services provide intensive treatment daily
 - 1 restricted to oncology patients only
 - 2 for both oncology and non-oncology related patients
- 18 services provide modified intensive treatment
 - 4 restricted to oncology patients only
 - 13 for both oncology and non-oncology
 - 1 restricted to non-oncology only

The therapists providing treatment are skilled to provide all levels of service and the variation in service is due to the lack of prioritisation of the lymphoedema service, lack of awareness, available funding and limited hours allocated. There is widespread under-utilisation of expertise in this specialist area which is a source of frustration for this cohort of passionate, committed therapists. The lack of allocated hours has implications for maintaining professional competencies and expertise. It also fails in exploiting opportunities for optimum patient care with consequent better patient outcomes, as will be detailed later in this report.

Service details, including staffing

Lymphoedema services are provided by a combination of disciplines - physiotherapists providing **50%** of services, nursing **23%** and combined nursing, occupational therapy and physiotherapy services accounting for **27%**. Services in Donegal (CHO1) are the only service in the country provided by a combination of physiotherapy and nursing. SIVUH and CUH are the sole services in the country with a combination of physiotherapy and occupational therapy provided services.

There are a total of 70 lymphoedema therapy staff across Ireland; 56 in general lymphoedema services and 14 in palliative services. Although the number of qualified therapy staff is adequate in some areas (e.g. in CHO 1), the actual hours dedicated to lymphoedema is low. There is no CHO lymphoedema service with enough hours to meet the estimated demand for lymphoedema/lipoedema services. Across all CHO's the total number of dedicated hours is 322.5 per week, which equates to 9 WTEs and in palliative care; 62 hours per week, equating to 1.7 WTE. The dedicated lymphoedema/lipoedema hours range from 2 per week to 37 per week, with only 3 CHO's providing a full time position. This equates to an average of 6.7 hours per week per therapist for lymphoedema/lipoedema services.

It should be noted that where services exist the allocated time to such lymphoedema/lipoedema services is not routinely collected and, therefore, was not readily available to the Working Group for its deliberations. The data was collected on a once-off basis from the different services. The absence of this data is symptomatic of the overall lack of data in relation to lymphoedema/lipoedema services. An overview of service provision is set out in **Table 8**.

Table 8: Overview of service provision by CHO/HG

CHO	CHO/Hospital	Service provision by discipline	Level of service- prevention/maintenance, modified intensive and intensive treatment	No. of trained Staff	No. of Dedicated Hours/week and WTE equivalent
CHO 1	Cavan PC	Physio	Modified intensive	1	2
	Monaghan PC	Physio	Modified intensive	1	2
	5 Donegal Networks	Physio/nursing	Modified intensive	21	44 (estimated)
	SUH	Physio	Modified intensive	1	2
Total				24	50 (1.3 WTE)
CHO 2	Mayo PC	Physio	Maintenance	3	0
	Roscommon PC	Physio	Maintenance	1	6
	GUH	Physio	Intensive	1	37
Total				5	43 (1.2 WTE)
CHO 3	UHL- Private therapist	Nurse	Prevention/Maintenance	1	8 (.2 WTE)
					8 (.2 WTE)
CHO 4	Private therapist Contracted , community based	Nurse	Modified intensive	1	4
	Mercy Hospital Ulcer clinic	Nurse	Modified intensive	3	10
	SIVUH	Physio/OT	Prevention/Maintenance	2	6
	UHK	Physio	Modified intensive	3	10
	CUH	Physio/OT	Modified intensive	3	12
Total				12	42 (1.1WTE)
CHO 5	University Hospital Waterford	Physio	Modified intensive	1	15
	Private therapist Community based	Nurse	Modified intensive	1	20
Total				2	35 (1 WTE)

CHO 6	*St Vincent's- Private Therapist contracted	Physio	Modified Intensive	2	8 (.2 WTE)
Total				2	8 (.2WTE)
CHO 7	St James'	Physio	Intensive	1	37
	St Luke's	Nurse	Maintenance	Trained to Level 2	25
Total				1	63 (1.7 WTE)
CHO 8	Portarlinton PC	Nurse	Modified intensive	1	24
	OLOLH	Physio	Modified intensive	3	10
Total				4	34 (.9 WTE)
CHO 9	Mater Hospital	Physio	Intensive	2	29.5
	Beaumont	Physio	Modified intensive	3	10
Total				5	39.5 (1 WTE)
Total		Physio;13 Nursing;6 Physio/occupational therapy; 2 Physio/nursing, 5	Maintenance; 5 Modified intensive; 18 Intensive; 3	56	322.5 hours per week (8.7 WTE)

**St Vincents hospital has 1 trained lymphoedema therapist but provides a very limited service (6 patients per year) and is, therefore, not included in the overall WTE number providing treatment but the therapist is included in overall qualified staff numbers.*

Lymphoedema Services in Palliative Care

- Palliative care services vary across the CHOs, a summary of the location of services, number of trained staff and number of hours dedicated to lymphoedema is presented in **Table 9**.
- There are 10 hospices in the country and half of these provide lymphoedema services. Of the 5 hospices that do not have an in-house service, 1 contracts a private therapist to provide services and 4 hospices refer patients to local hospital services for lymphoedema care.
- There are 3 physiotherapists in palliative care teams providing services for lymphoedema patients - 2 in CHO 8 (Louth and Meath) and 1 in CHO 1 (Cavan/Monaghan).
- 1 physiotherapist in primary care providing services to patients in palliative care in CHO 1 (Donegal).
- There are no HSE palliative care lymphoedema services in CHO 2 or CHO 5.
- There are 14 trained lymphoedema therapists in palliative care services nationally with an estimated 62 dedicated hours per week, an average of 4.4 hours of services provided by each therapist per week. This equates to 2.4 WTEs.
- The palliative homecare services were not in a position to provide the estimated hours per week as this was not routinely recorded and varied depending on the case load.

Table 9: Lymphoedema services in palliative care

CHO	In-Patient Unit Service	Service provision by discipline	Hours per week	Community lymphoedema services	Service provision by discipline	Hours per week
CHO 1	Donegal Hospice, Letterkenny	No services	-	Donegal county only	1 Physiotherapist Primary care	No recorded hours
					PHN as required	8 hours
	North West Hospice, Sligo	2 therapists	6-8	Cavan/Monaghan counties only	*1 physiotherapist as part of Palliative care team	No recorded hours
CHO 2	Galway Hospice, Galway	No services	-	None		-
CHO 3	Milford Care Centre, Limerick	4 physiotherapists	37	None	-	-

CHO 4	Marymount Hospice, Cork	No service-refer to CUH	-	None	-	-
CHO 5	University Hospital Waterford	No service-Patients are referred to private therapist		None		
CHO 6	Our Lady's Hospice and Care Services, Blackrock	*2 physiotherapists Maintenance treatment only		None		
CHO 7	Our Lady's Hospice and Care Services, Harold's Cross St Brigids Hospice, Kildare	2 Physiotherapists across both sites	8	None		
CHO 8	None			Counties Louth and Meath	2 physiotherapists as part of palliative team service	No set hours-
CHO 9	St. Francis Hospice, Raheny	2 nurse therapists	1.6 Out-Patient 2.4 In-Patient	None		
	St Francis Hospice, Blanchardstown	1 nurse therapist	30 hours Out-Patient /In-Patient			
TOTAL		11 therapists in hospices	87 hours/ week		3 therapists PC	8 hours

**The service provided is for advice and garments only, the therapist is not certified in lymphoedema.*

Compression garments

Compression garments are an essential component of lymphoedema/lipoedema management to control oedema by exerting graduated pressure on the tissues to stop fluid build-up and encourage fluid to drain. They should be replaced every 6 months and prescribed by a therapist appropriately educated in compression garments. A UK survey revealed that 50% of lipoedema patients who used compression garments found them unhelpful, most often due to poor fit. Patients who received garments from specialist clinicians based in a lymphology clinic had a better experience (Fetzer & Wise, 2015).

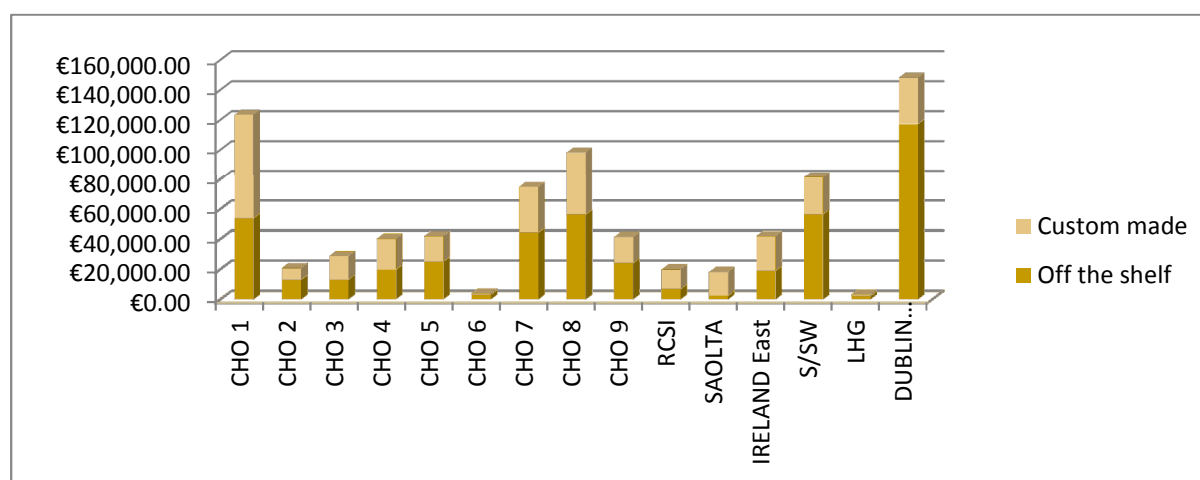
From the survey there is inequity of garment provision to patients across the country with variations of 1, 2 or 4 garments provided to patients per year depending on the service location. Provision of garments also varies between community and acute services, with more patients paying for garments in the community compared to acute services. There are also no standard national procurement arrangements for garments and no agreed standards for compression garment prescribing.

The total spend in 2016 on compression garments was €800,000 across all services, with huge variation on individual product costs and also on overall spend across CHOs and HG's ranging from €3,240 up to €148,225. The range of cost in the HG's was from €3,240- €148,059 and in the CHO's €4,132- €123,143. Spend on custom made

garments versus 'off the shelf' garments varied hugely across areas, dependent on the service being provided and overall characterised by an absence of clear formal policies and standards. Figures from other countries indicate that a ratio of 30:70 is expected in a lymphoedema service of custom made garments to 'off-the-shelf' garments. 6 of the CHO/HG areas spend more on custom made garments which would indicate that there is over-reliance on custom made garments which are very costly in comparison to 'off- the-shelf' garments (**Figure 6**).

The data on expenditure for custom made and 'off the shelf' compression garments was obtained from 6 companies providing garments and its accuracy was not possible to be verified by the CHOs/HGs. A work stream of the Community Funded Scheme Service Improvement Programme is reviewing the provision of compression garments to standardise the prescribing, determine standard operating practices and enter a procurement process in relation to the provision of compression garments.

Figure 6: Spend on compression garments



Waiting times

As reported in the on-line survey, waiting times vary across the country from 1 week to 2 years for non-oncology related lymphoedema and 1 day to 6 months for oncology related lymphoedema. 3 services were unable to report on waiting times as numbers of lymphoedema referrals and waiting times were not recorded. Some services prioritised in-patient services over out-patient services and their waiting times varied from week to week, depending on in-patient demand.

Referral source

Referrals to services, where recorded, came from a variety of reported referral sources. The proportion of referrals accepted from a range of services is reported in the survey as follows:

- 87%** accepted referrals from Oncology
- 45%** accepted referrals from HSCP's
- 37%** accepted referrals from Vascular services
- 33%** accepted referrals from PHN
- 25%** accepted referrals from Dermatology services
- 20%** accepted referrals from Self-referrals
- 17%** accepted referrals from GPs

This reflects the inequity of access which is higher for oncology related patients and lower for non-oncology patients.

Standards of care

Only 7 of the 24 services that returned the survey indicated that they used standards or guidelines for treatment and management of lymphoedema/lipoedema services. This means that 17 of the 24 respondents or 71% of services do not use standards for service provision.

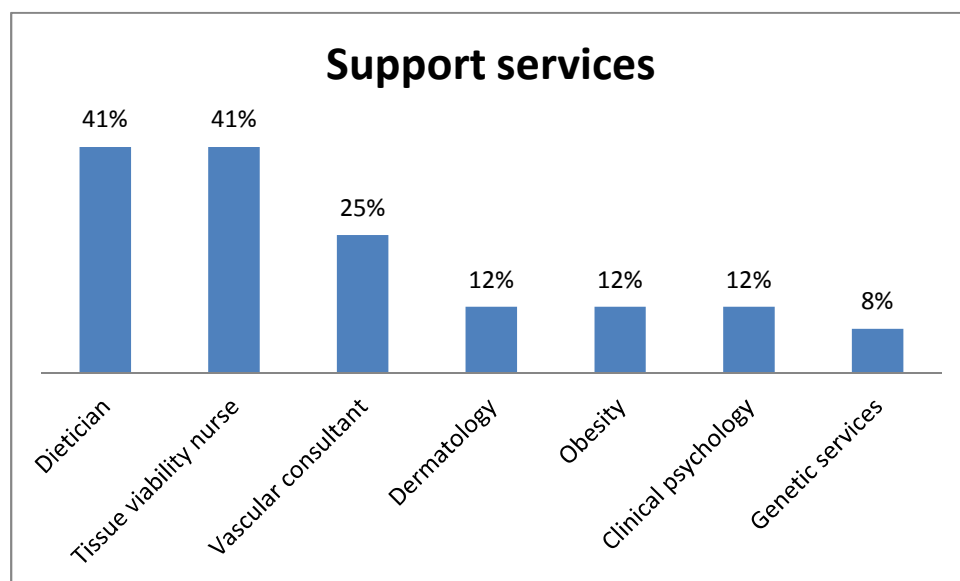
Access to support services

The survey found that there is a lack of access to other support services for lymphoedema/lipoedema patients. Many of these services are critical for a multi-disciplinary approach to the effective management of patient conditions. The following is a summary from the 24 survey respondents of their perceived access to support services. These support services are listed by speciality and detailed in (Figure 7).

- **41%** reported access to a tissue viability nurse service
- **41%** reported access to dietetic services
- **25%** reported access to vascular services
- **12%** reported access to dermatology services
- **12%** reported access to clinical psychology services
- **12%** reported access to obesity services
- **8%** reported access to genetic services

The respondents reported that while there are services available long waiting lists prevail for many support services and act as a barrier for access to comprehensive treatment and care. It should be noted that while the respondents reported on their perceived access to the range of services, some services may be available without the respondent's knowledge.

Figure 7: Access to support services



Identification of high risk patients

13 of the 24 reported services (54%) did not utilise a system to identify and record high risk patients. The 11 services identifying high risk patients were primarily oncology services and it was established there were no consistent standards being used by these services.

Lymphoedema Treatment Abroad

The HSE operates a Treatment Abroad Scheme (TAS) for people entitled to treatment in another EU/EEA member state for patients with severe disease and who are in need of highly specialised services. The TAS provides the cost of approved treatments in another EU/EEA member state or Switzerland. The scheme allows Irish consultants to refer a patient who is normally resident in Ireland for treatment in another EU member state or Switzerland, where the treatment in question meets certain criteria. Approval under the provisions of the TAS is automatically granted to lymphoedema patients that fall into the following categories, those that suffer from primary lymphoedema and paediatric lymphoedema cases. Also automatic approval is granted for access to micro surgery and liposuction in respect of all lymphoedema cases. The number of patients who had treatment for lymphoedema under the TAS together with details of expenditure for the years 2012-2017 is shown in Table 10.

The HSE also operates a Cross-Border Healthcare Directive (CBD), for people entitled to public patient healthcare in Ireland who want to avail of that healthcare in another EU/EEA member state. For patients seeking to access intensive programmes abroad for lymphoedema care, including intensive physiotherapy, lymph drainage and compression garments/bandages, may avail of such services under the CBD.

Table 10: Data from the Treatment Abroad Scheme (TAS)

Year	No of patients	Cost €
2012-2017	26	103,429

Private Therapists

Four of the services surveyed are provided by private therapists that are contracted by CHOs and HG's to provide services. There is no mandatory professional regulation of lymphoedema therapists in Ireland at the current time. These out-sourced services are much more costly than directly provided services. In 2016 in CHOs 4 and 6 an average hourly cost for a private therapist was €107, greater than 3 times the hourly cost of a HSE lymphoedema therapist. It is estimated from the survey responses that 40 hours per week were provided by private therapists, costing €222,560. This cost would be sufficient to employ more than 3 full-time lymphoedema therapists.

3.3. A Review of Lymphoedema Education in 3rd Level Course

As appropriate education for health professionals is critical in identifying and managing lymphoedema/lipoedema in patients it was important for the Working Group to establish the extent of such education in relevant 3rd level education programmes. 4 universities out of the original 7 universities contacted responded to the information requests on the provision of lymphoedema/lipoedema education. In addition curricula from 2 nursing degree courses were examined for lymphoedema education content and these were added to the findings from the review Table 11.

Due to the extensive number of nursing programmes only the current education standards for nursing in Ireland, which informs the curriculum, was reviewed. Lymphoedema is not included in the current 2015 standards or in the new standards proposed for 2018. There is also an oncology post-graduate nursing course which includes an hour lecture in oncology related lymphoedema.

Table 11: Current lymphoedema 3rd Level education provided in Ireland

Physiotherapy and Occupational Therapy			
University	Profession	Course	Hours per course
UCD	Physiotherapy	Degree	18 hours
Trinity College	Physiotherapy	Degree	1 hour
RCSI	Physiotherapy	Degree	2 hours

University of Limerick	Physiotherapy	Degree	Part of a case study Hours undefined
	Occupational therapy	Degree	2 hours
Nursing			
University	Profession	Course	Hours
UCD	Nursing	Post Graduate Diploma Oncology Nursing-	1 hour
Trinity College	Nursing	Post Graduate Diploma Oncology Nursing-	1 hour
University College Cork	Nursing	Post Graduate Diploma Oncology Nursing-	1 hour
National University of Ireland Galway	Nursing	Post Graduate Diploma Oncology Nursing-	1 hour

Key Points from the survey of current services and review of 3rd Level education:

- There are 26 existing lymphoedema services in Ireland.
- There is inequity of access across the country with service distinctions being made between oncology and non-oncology related lymphoedema. Oncology related lymphoedema services are restricted in some areas to patients with particular cancers such as breast cancer.
- There are no lymphoedema services in 5 CHO areas.
- There are 56 certified lymphoedema therapists in Ireland employed by the HSE (3 on contract). There are also 14 certified therapists working exclusively in palliative care.
- There are only 3 services with full time dedicated hours for lymphoedema; 1 for breast care lymphoedema only and 2 for oncology and non-oncology.
- The national hours dedicated to lymphoedema services are 322.5 per week, (equivalent to 9 WTEs), an average of 6 hours per therapist per week.
- Palliative lymphoedema services vary in provision in each CHO between hospice provided and primary care provided. There are no lymphoedema palliative care services in 2 CHOs.
- 5 of the 26 services only provide Maintenance Treatment services.
- Provision of compression garments varies across all services and is not in line with international standards. Funding levels for garments varies hugely across acute and primary care services. There are no national standard procurement arrangements for compression garments.
- There are long waiting times in some services; up to 2 years for non-oncology related lymphoedema and from 1 week-6 months for oncology related lymphoedema.
- The source of referrals varies in each service with high access for oncology related referrals and low access for non-oncology related referrals.
- 71% of services do not use standards for service provision.
- There are significant access issues to MDT support services.
- More than half of the services do not identify high risk patients.
- There is a lack of lymphoedema awareness, treatment and management in undergraduate and post-graduate education programmes.

3.4. Conclusion

The existing lymphoedema/lipoedema services are inequitable, disjointed, not standardised and lack defined structures. There is no consistency across services with significant variations in referral source, treatment provided, compression garment provision, access to support services and risk identification. There are skilled therapists in the work force, with some CHO areas having adequate trained staff for the population demand, but a lack of dedicated hours. Only 3 services provide daily sessions for intensive treatment. The lack of dedicated working hours and the lack of consistency in service provision can lead to loss of skill, competence and confidence for staff (Murray, 2010).

There are some areas providing good services that are evidence-based and there are therapists in the current workforce that are highly skilled, dynamic and keen to see improvements in the structure of the lymphoedema/lipoedema services to improve patient care.

Prevention and identification of high risk patients is a priority for effective chronic disease management but this is not evident in over **50%** of the services.

Palliative lymphoedema services vary across the country with highly trained staff employed but not enough dedicated hours are allocated to lymphoedema/lipoedema services. Palliative care services should be integrated with specialist lymphoedema services to benefit the patients and staff.

Although there is access to all support services in the HSE the survey results indicate that therapists are not aware of how to appropriately access these services. The waiting times, however, are considered to be excessive and patients are not referred to support services. This indicates difficulties in the integration of and access to services. There are clearly significant deficits in the provision of these support services and the arrangements for integrating them with the existing lymphoedema/lipoedema services.

From the preliminary findings there is a lack of lymphoedema/lipoedema education in under-graduate education. This has led to a lack of awareness of these conditions among clinicians, which is reflected in the paucity of services, poor and non-existent coding and referral to inappropriate services. A full review of all relevant undergraduate programmes, including medical and other HSCPs, should be carried out to establish the current level of education for lymphoedema and to address such deficits in course curricula in order to improve the awareness, management and treatment of these conditions.

There is large variation in the provision arrangements for compression garments nationally. There is evidence of significant over-prescribing of more expensive custom made garments in some areas. Some areas are not prescribing the recommended number of garments per year i.e. 2 garments every 6 months. Introducing standardised criteria for prescribing will have benefits for patients, reduced waiting times for garments, improved compliance and cost efficiencies.

The TAS and CBD services, while filling a service need for patients, are expensive compared to HSE funded local services. They are not sustainable for patients with lymphoedema/lipoedema where care should be on-going and available locally for support and self-management. Patients attending TAS and CBD funded services typically receive two to three weeks of intensive treatment with good results but due to lack of local services there is minimal follow up to maintain the improvement and typically the patients' conditions deteriorate and regress. The absence of regular local services leads to a cycle of requiring regular intensive treatment abroad which is not sustainable and provides undue hardship for patients. The demand for TAS and CBD for lymphoedema treatment is increasing due to the current lack of services available in Ireland and an increase in awareness of the services available outside of the country.

Due to the large gaps in public services across the country private therapists, in some areas, fill these gaps under contract to the HSE. They play an important role in managing lymphoedema/lipoedema in the absence of HSE structured services albeit at a higher cost than directly employed HSE therapists. MLD Ireland Limited is the

professional organisation for people who have training in lymphoedema and currently they have 44 registered therapists but membership is voluntary and therefore it is not possible to establish the total number of private therapists. Private lymphoedema therapists do not have mandatory regulation.

Despite the lack of dedicated time and resources there are areas of good practice in the country which could be replicated in other services with standardisation, leadership and resources.

A Model of Care is essential to address these and other issues and to provide the required guidance and detail on how best to manage lymphoedema/lipoedema services in Ireland. This is addressed in the next chapter which examines best practice and international guidelines and documents the model of care.

4. Provision of optimal care for Lymphoedema/Lipoedema

4.1. Background

The International Lymphoedema Framework (ILF), Lymphoedema Network Northern Ireland (LNNI) and the British Lymphology Society (BLS) all provide guidance on lymphoedema services which underpin this Model of Care. The guidance has been adapted to the Irish context.

There are Best Practice Guidelines for Lipoedema, published 2017, which are referred to in this document (Wounds UK, 2017). Lipoedema treatment is similar to lymphoedema and, according to the UK Best Practice Guidelines 2017; services are best placed within a lymphoedema service. All services referred to in this Model of Care document are, therefore, inclusive of lipoedema services.

The Model of Care, (as detailed in Chapter 5), for the future management and treatment of lymphoedema services has been formulated using several factual and evidence-based inputs. These include a review of population needs, current prevalence data, information from the national survey to identify gaps and comparison to current international best practice and similar services in the UK.

A stakeholder workshop was also held to establish the opinions of all main stakeholders and to ensure that these views were encompassed in the Model of Care. The workshop validated that the proposed Model of Care and recommendations met the main stakeholders' vision of a comprehensive lymphoedema/lipoedema service (**Appendix 4**).

4.2. Essential elements of the Model of Care

The aim of this section is to describe the current best practice under the four essential elements needed to provide a comprehensive lymphoedema/lipoedema service:

1. Prevention and early detection
2. Assessment
3. Treatment and support services
4. Education and research

Each element has been evaluated using the available guidelines and optimal care and practice is described for each one. A gap analysis has been completed for each element and the recommendations outlined.

4.2.1. Prevention and early detection

It has been shown that screening, monitoring and preventative strategies in high risk areas can reduce the chance of developing lymphoedema (Stout 2008, Norman 2009) and, if detected and treated early, will keep symptoms controlled and prevent escalation of the condition. High risk areas include primarily oncology but also care of the elderly, vascular, wound care and wheelchair bound patients. Early diagnosis and intervention for lipoedema is recommended in the guidelines (Wounds UK, 2017).

In oncology a full prospective surveillance model is recommended for lymphoedema/lipoedema (Armer, 2013) which includes pre-operative and post-operative assessment, education, clinical monitoring, early identification and referral. This is recommended by the National Lymphoedema Network in America. To implement this in Ireland would require resources for education and dedicated staff working in oncology centres and needs to be reviewed with the National Cancer Control Programme for future planning.

There are simple screening tools that can be used to identify if a patient is at high risk of developing lymphoedema. If patients are identified as being high risk they should be referred to a lymphoedema therapist to be assessed for sub-clinical lymphoedema (Clinical Group 1) which can be detected using a variety of methods e.g. bio-impedance or moisture meter. Lymphoedema detected sub-clinically can be treated with compression, exercise and education to prevent the condition developing and patients consequently require minimal follow up.

If patients who develop lymphoedema are not detected early, the lymphoedema will progressively worsen, leading to complications, often debilitating, with significant impact on patients' quality of life. Delayed treatment will require increased utilisation of specialist lymphoedema services and MDT support with potential poor outcomes for the patients, increased hospitalisations due to related complications and increased costs for the health service.

A proportion of people with primary lymphoedema will have a genetic predisposition. There is also a genetic disposition to lipoedema in some patients (Smeller-Vollrath, 2007) and there is scope for reducing future incidence through genetic counselling which should be made available for patients as appropriate.

Optimal care for prevention and early detection

- All patients should have access to information regarding prevention, self-detection and the pathway for access to rapid services.
- The risk of lymphoedema should be included in the pre-operative consent form for surgeries that involve the lymphatic system.
- All healthcare staff should be educated to a minimum standard and should be able to recognise lymphoedema/lipoedema, give basic advice and know the appropriate referral pathway.
- All patients at risk of developing lymphoedema should be screened and, if appropriate, referred to lymphoedema services.
- All high risk patients should be assessed for sub-clinical lymphoedema using appropriate methods e.g. bioimpedance or moisture meter.
- A defined referral pathway should be in place that is equitable and accessible irrespective of age, gender, sexuality or ethnic origin, disability, weight or aetiology.
- Patients with primary lymphoedema/lipoedema should have access to genetic counselling.

Gap analysis

From the survey just over half of the services in Ireland identify high risk patients and there were no consistent standards being used for detection and onward referral. There are no known HSE services using methods to detect sub-clinical lymphoedema. This indicates that patients are currently undiagnosed at early stage lymphoedema which leads to more intensive and prolonged services than if detected earlier.

Lymphoedema prevention and early detection recommendations:

1. The risk of lymphoedema should be included in the pre-operative consent form for all surgeries that involve the lymphatic system.
2. All patients should have access to information on lymphoedema risk, prevention and self-detection.
3. Prevention awareness and screening tools should be developed in all high risk areas e.g. oncology units, vascular departments, older people service facilities.
4. Early detection protocol, stage 0, for patients assessed as high risk should be developed with appropriate referral pathways for rapid assessment.
5. Genetic counselling should be made available for patients with primary lymphoedema and lipoedema as appropriate.

4.2.2. Assessment

Optimal care for assessment

For an effective care plan it is essential that a comprehensive assessment is available to all patients identified as at risk or with lymphoedema (MEP, 2006). Comprehensive assessment includes medical and therapist assessment as set out below.

Medical Assessment

- A medical assessment is important for differential diagnosis and to exclude other pathology. This should include a medical history and a physical examination. Depending on the presentation other investigations may be required.
- Specialist investigations may be needed depending on the severity of the oedema. This can include Ultrasound, Doppler, Lymphoscintigraphy, CT/MRI and Bioimpedance.
- Primary lymphoedema may require genetic screening and counselling.
- The diagnosis of lymphoedema in children is often delayed due to lack of awareness and specialists services (Murray, 2009). There are many forms of primary lymphoedema but the two main causes in children are Milroy's disease and lymphoedema distichiasis and it is essential to include underlying genetic causes and inheritance patterns to ensure an accurate diagnosis.
- Lipoedema is diagnosed on clinical presentation; there are no diagnostic tests available at this time.

Lymphoedema therapist assessment

- Assessment should be carried out by a therapist with ILF recognised lymphoedema training in a dedicated lymphoedema/lipoedema clinic with access to multidisciplinary staff (Dietician, Podiatrist, Psychologist, Occupational Therapist, Social Worker, Geneticist and appropriate Consultant).
- Access to services should be timely.
- The assessment findings should be recorded systematically and form the basis of the care pathway. Referral pathways to identified health professionals e.g. dietician, psychosocial, should be in place for continuity of care and communication.
- Quality of life and psychological impact tools should be used to have a baseline to measure treatment outcomes. The validated quality of life measure for limb lymphoedema (LYMQOL) should be used as a standard outcome measure. (Keeley, 2010).
- Psychological support should be available using a standardised algorithm for assessment and referral (ILF, 2006.)

- There should be consistent data collection of patient demographics using computer programmes to aid standardisation. (The BLS recommends using the National Lymphoedema Partnership (NLP) minimum data set).
- MDT meetings should be held regularly to discuss complex patients, their assessment and individual care plans and also to share learning with the team and improve co-ordinated patient assessment and care management.

Cellulitis assessment

As previously described cellulitis is a major complication of lymphoedema and, conversely, patients with recurrent cellulitis can develop lymphoedema.

- Lymphoedema assessment should be incorporated into the cellulitis care pathways for patients that have a history of oedema, recurrent cellulitis or lymphoedema that is not managed.
- These patients should be assessed by a lymphoedema therapist and provided with appropriate treatment and follow up.

Improved patient outcomes, reduced reoccurrence and reduced unnecessary hospital admissions have been demonstrated in many services that have implemented this pathway. Studies have shown reductions in admissions for cellulitis of up to **87-100%** (O'Neill, 2015, Thomas, 2016, Moffatt 2016). In Ireland an estimated 1,451 patients a year are admitted to hospital with cellulitis related to lymphoedema/chronic oedema. The average length of stay is 11 days, longer than the average due to the complexity of these patients and costing over €13.6M per annum. The Working Group estimates that this cost could be reduced significantly saving up to **87%** (O'Neill 2015) if comprehensive assessment and lymphoedema treatment services were introduced, with potential savings of €11.8M based on these figures.

Gap analysis

- According to the results of the survey conducted and subsequent confirmation with the wider health system there are no consultant medical lymphoedema specialist services available in Ireland. Lymphoedema is associated with a number of specialities; oncology, vascular and dermatology but there are no identified medical services dedicated to lymphoedema.
- Patients with non-oncology lymphoedema have no access to services in CHOs 5, 6, 7 and 9.
- Oncology patients that are not breast-oncology care patients have no service in CHO 6.
- Lipoedema patients do not have a service in CHOs 2, 3, 5, 6 and 7.
- Waiting times can be up to 6 months for oncology related lymphoedema and up to 2 years for non-oncology related lymphoedema.
- There are no consistent standards being used for assessment and treatment plans.
- There is no minimum data set for service analysis and patient profile.
- Most of the acute services have an identified referral pathway but these are primarily for oncology related lymphoedema.
- There are no services with a paediatric assessment speciality.
- Lymphoedema assessment is not included in cellulitis care pathways currently.

Assessment recommendations:

1. One Specialist Lymphoedema Clinic (SLC) to be established in each CHO, in a community location for assessment, intensive treatment and education for all types of lymphoedema and lipoedema.
2. Acceptable assessment waiting times should be identified when the standards for lymphoedema are agreed.
3. A clear referral pathway from the SLC into identified MDT support services should be documented.
4. An IT enabled standardised assessment and care plan tool needs to be procured and deployed.
5. A minimum data set needs to be recorded on each patient.
6. Recognised standard outcome measures should be agreed and introduced in all the lymphoedema services.
7. One SLC will provide paediatric lymphoedema assessment services as a national sub-speciality service.
8. Lymphoedema assessment to be included in cellulitis care pathways for appropriate patients.

4.2.3. Treatment and support services

Optimal care for treatment

The available research to validate the effectiveness of different lymphoedema treatment methods displays mixed results. There are many reasons for this, including a lack of agreement in terminology, a lack of reported outcomes, the methods for assessment and protocols used (Sierla, 2017). Although there is some lack of consensus standardisation is required and can be achieved on those areas of agreement as follows:

- ✓ There is a sound knowledge of physiological principles and international expert experience and opinion to support the efficacy of the proposed treatments. (CREST, 2008; MEP, 2006).
- ✓ There are NICE clinical guidelines for breast cancer which recommends CDT, MLLB and compression garments for the treatment of lymphoedema. All patients should have an appropriate bespoke treatment plan in place with early involvement of family members and self-management (MEP, 2006). Therapists should use an agreed lymphoedema treatment algorithm as set out by the ILF (2006) and the Best Practice Guidelines for Lipoedema (2017). See **Appendix 4**
- ✓ Self-management strategies have been shown to be effective in chronic disease (De Walt, 2004). A study in Canada developed a home-based standardised self-management protocol for people with limited mobility to manage and prevent swelling of the lower limb using tele-rehabilitation. Their results supported the use of tele-rehabilitation (Faett, 2012). In October 2012, the Macmillan Lymphoedema Project for Scotland produced “Top Tips for the Self-Management of Lymphoedema – A Guide” which is aimed at people living with lymphoedema, their carers, and healthcare professionals. Exercise has also been shown to have a significant benefit for self-management in lymphoedema (Douglass, 2016).

Following on from these areas of agreement the following evidence-based recommendations are deemed to be appropriate:

- Patients should have access to daily intensive treatment under a clearly defined pathway in a specialist lymphoedema/lipoedema clinic and once stabilised be referred to their local community services for maintenance, support and self-care.

- All therapists should be trained appropriately in the measurement and prescribing of garments with knowledge of procurement standards and guidelines on garment provision.
- All eligible patients should be provided with a minimum of two garments at least every six months (MEP, 2006), depending on the severity of the oedema and should be re-measured prior to a new garment being issued.
- Treatment should be carried out in an appropriate setting with adequate staffing and facilities.
- Recording of treatment outcomes should be standardised across all services using the ILF guidelines, ensuring best practice is pursued and achieved and allowing national and international benchmarking.
- Self-management strategies should be encouraged at all stages of the pathway.

Paediatric Lymphoedema Treatment

The recommended treatment for children with lymphoedema is similar to adults and while there are no specific paediatric treatment guidelines available there are specific requirements, including;

- Reassessment for compression garments needs to be more frequent due to active growth.
- Parental education, support and involvement in managing this life-long condition.
- Psychosocial intervention is important as this cohort of patients can experience low self-image and self-esteem. Their ability to be involved in activities can be restricted and their need to wear visible compression garments can lead to psychosocial issues.
- It is recommended that children are seen in a national specialist clinic with dedicated staff which will ensure standardised care, psychological support including meeting other children with lymphoedema and help to maintain a skilled workforce (Murray, 2009). There also needs to be co-ordination with local services to ensure continuation of care into adulthood. This should be successfully effected in Ireland in the National Children's Hospital with established links to a Specialist Lymphoedema Clinic having its staff trained in paediatric treatment.

Gap analysis

It is evident from the survey results that the available treatment services are not provided equitably and there are huge service gaps.

- Some areas do not provide treatment depending on the aetiology of the lymphoedema or do not provide treatment for lipoedema patients at all.
- Only 3 services offer daily intensive treatment. Some services do not offer treatment for complex stages of lymphoedema i.e. any intensive treatment for moderate to severe conditions. There are no specialist paediatric treatment services available.
- There are no consistent standards being used for treatment or outcome measures.
- Some services do not review patients every 6 months.
- There are no national standards for the provision of garments after initial assessment and review.
- There are delays in garment provision due to existing HSE funding approval processes, which vary across CHOs.
- There are inadequate primary care services to accept referrals from specialist lymphoedema services to provide maintenance treatment in a timely manner.
- 4 services are funded by the HSE and provided by private therapists who are not subject to adequate HSE clinical governance.
- The current hours of staffing dedicated to lymphoedema services are inadequate to provide comprehensive services to all patients.

Treatment Recommendations

1. An agreed lymphoedema algorithm should be introduced to ensure standardised best practice.
2. One SLC should provide specialist paediatric services.
3. All lymphoedema specialist clinics should offer daily intensive treatment for oncology and non-oncology related lymphoedema.
4. Guidelines for the prescription of compression garments need to be agreed and introduced.
5. All patients should be reviewed at least every 6 months and measured for compression garments in their local community lymphoedema services.
6. All eligible patients should be provided with 2 garments every 6 months.
7. Additional funding should be available for eligible patients for garments every 6 months
8. The SLCs will link with local patient support groups e.g. Lymphoedema Ireland, in self-management of their condition.
9. Guidelines for the management of obesity related lymphoedema should be agreed and introduced.
10. All SLC's should be appropriately equipped with access to bariatric equipment, electric beds, measuring equipment, IT data systems etc.
11. Psychosocial support, working with local support centres and support groups should be available to patients.
12. Self-management innovations such as eLearning, educational videos and apps should be developed.

The Working Group determined from research, the professional survey and the university education review and engagement with stakeholders that health care professionals in Ireland do not have sufficient knowledge to identify, assess and contribute to the treatment and management of lymphoedema/lipoedema.

It is internationally recognised that education on the lymphatic system and lymphoedema is poorly addressed in health professional education curricula. To address this the ILF has identified Lymphoedema Education Benchmark Statements (LEBS) that could be used in an Irish context.

Lipoedema UK's Big Survey 2014 revealed that only **5%** of doctors were aware of Lipoedema. Lipoedema UK has developed GP eLearning courses. This should be replicated in Ireland.

In order to manage lymphoedema/lipoedema at all stages and levels of treatment it is essential that the education input reflects in detail the recommended treatment and management regimes, is comprehensive and is across all disciplines to improve the quality of care for patients.

There are broadly three levels of education required to ensure that lymphoedema is diagnosed, treated and maintained according to best practice guidelines. These are outlined in **(Figure 8)** and further detailed in **Table 12**.

All therapists providing lymphoedema services must be qualified in line with the '*Best practice for the management of lymphoedema*' (2006) and should have access to reviews every 2 years.

Figure 8: Education Levels

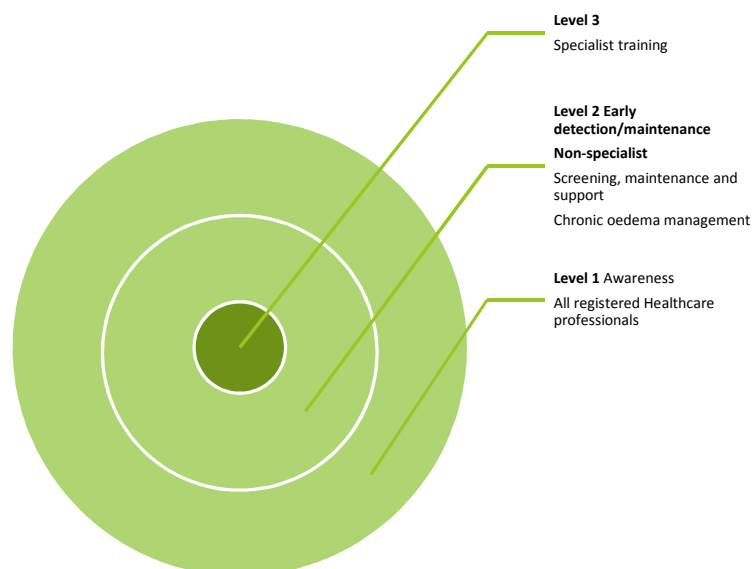


Table 12: Lymphoedema/Lipoedema education levels

Education Level	Health care professional	Education required
Level 1	All health care professionals (HCP)	Basic awareness education for all healthcare workers that should be provided at undergraduate level. There are education benchmark statements for lymphoedema produced by the ILF (2017). These are available on the ILF website for reference and are a simple and inexpensive way to integrate the information into a curriculum.
	GPs	Early diagnosis and knowledge of appropriate pathways for lymphoedema, lipoedema and cellulitis. There are currently on-line GP education tutorials that can be accessed through e-learning modules. These should be developed for an Irish context.
	Oncology services	Education on screening tools, basic preventative care and referral pathway.
	HCPs in other high risk areas	Basic preventative care, awareness and knowledge of the referral pathway.
Level 2	HCPs working in primary care location clinics	1 day introductory lymphoedema course to include; measurement of limb volumes, prescription of compression garments and provision of support and education.
	HCPs working in wound care/chronic oedema	1 day course to manage and treat chronic oedema to include assessment, compression/bandaging and exercise for the lower limb.
Level 3	Lymphoedema therapist	All therapists in lymphoedema must be qualified in line with the 'Best practice for the management of lymphoedema' (2006) and should have access to reviews every 2 years.

There are positive opportunities for Level 3 Therapists to provide teaching and mentoring for staff to be trained at Levels 1 and 2. This would help to improve professional working relationships and provide consistency in education content and also provide continuity as changes in staff occur. Refresher courses may be needed for therapists that are working in specific areas of lymphoedema to enable them to work in all areas of the service.

The competencies and methods of learning for each level of education should be agreed with the development of the standards of care and can be adapted from the recommendations of the ILF (Sneddon, 2007).

On-going research needs to be pursued to ensure best practice so that patients can access up to date treatment. Partnerships between universities and the lymphoedema services should be established to identify research needs for the development of services. The Lymphoedema Research Prioritisation Partnership project '*Shaping the future of lymphoedema research in the UK*' is due to be published in 2018 and will recommend their top 10 research priorities in this area. Due cognisance should be taken of these priorities and opportunities for joint research projects should be explored with UK colleagues.

Gap analysis

- Level 1- From the survey results there is a lack of lymphoedema/lipoedema education in undergraduate courses for all HCPs.
- Level 2- The need for education to manage chronic oedema has recently been recognised in Ireland and a course is available in UCD which started in September 2017. This or similar courses could be rolled out nationally. The need for non-specialist therapists to provide maintenance treatment for lymphoedema and lipoedema is not yet formally recognised and there is no training available at this time. A module for education at this level has been introduced in Scotland and a similar course could be implemented in Ireland.
- Level 3- There are 70 trained therapists in Ireland, working across general and palliative lymphoedema care services. This is sufficient to provide services based on population need as identified in this report if all were working close to maximum weekly hours on lymphoedema/lipoedema services. Refresher courses may be needed for existing staff and provision for this should be made in the compilation of the overall education plan.

Although a full literature review of current research has not been undertaken as part of the deliberations of the working group it seems that there is no current research being undertaken in Ireland on lymphoedema or lipoedema services.

Impact of Education

Implementation of an education plan to address the deficits at the 3 levels of education described will lead to a dedicated workforce for assessment and treatment of complex patients and an appropriately trained workforce for the maintenance stage of care. This will ensure the appropriate use of resources and skills. The Northern Ireland health services introduced an education strategy which included several training levels, including training for lymphoedema therapists and general training for all clinical under-graduate staff in prevention and diagnosis. The education strategy was credited with the early identification of many cases, resulting in an increase in referrals with consequent better patient outcomes due to early intervention. The increased awareness also resulted in more non-oncology related patients being referred and treated early. The composition of patient referrals altered consequently from **90%** oncology related lymphoedema referrals to **54%**, achieving a balanced mix commensurate with population health planned predictions. The benefits and learning from the Northern Ireland approach should be explored with a view to transferring these to the Irish health services.

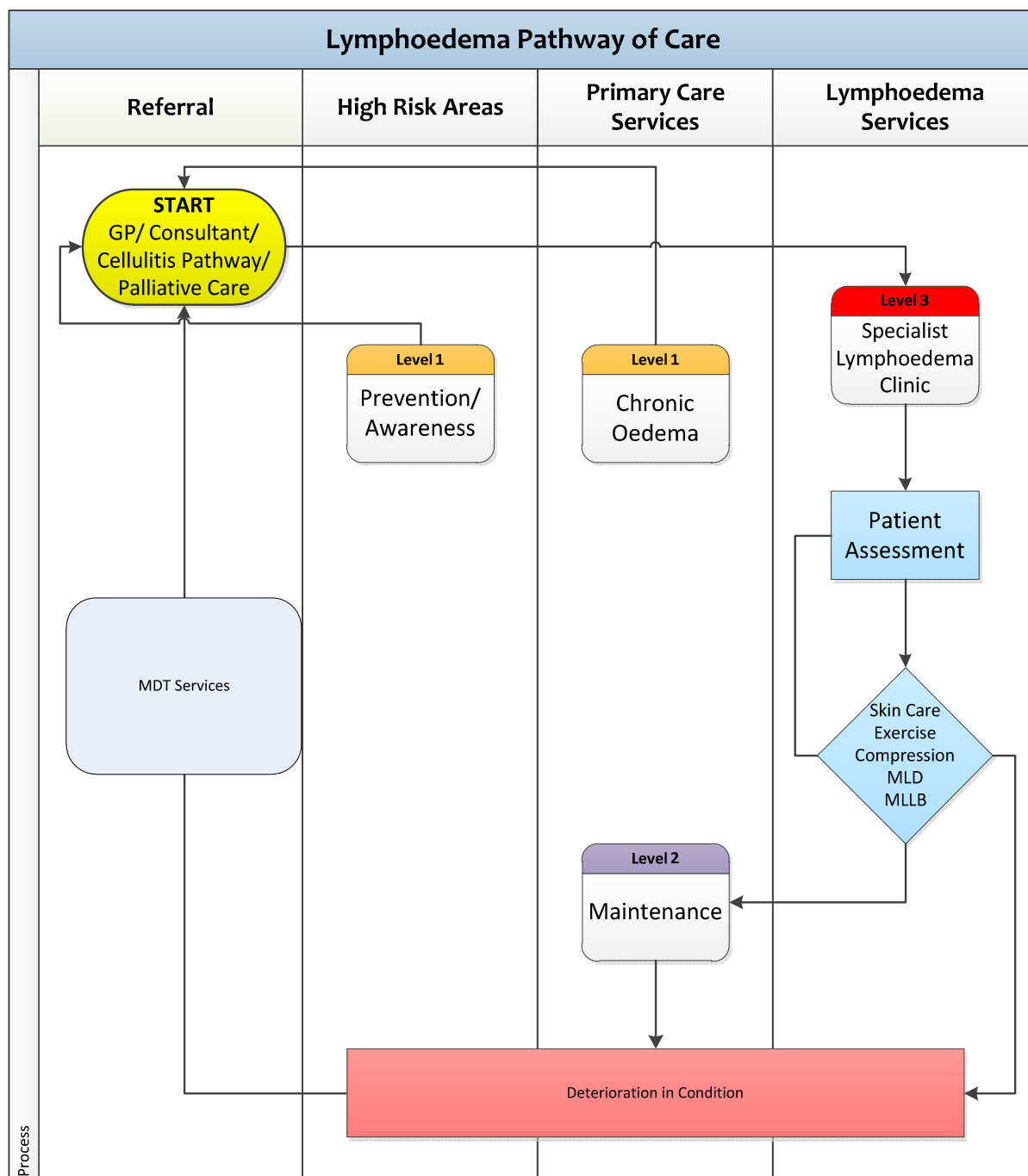
Education Recommendations

1. An overall education plan for all stakeholders including patients, lymphoedema therapists, support clinicians should be devised nationally and implemented for the 3 required levels of training.
2. All undergraduate programmes should include a standardised lymphoedema module.
3. A GP online training programme for early detection and referral of lymphoedema should be developed and made available to all GPs.
4. A 1 day level 2 education programme for identified staff in community settings for maintenance treatment should be developed.
5. Research opportunities to be explored with universities in Ireland and abroad to improve lymphoedema and lipoedema care.

Lymphoedema Care Pathway

A Specialist Lymphoedema Clinic should provide treatment for all lymphoedema patients, oncology related and non-oncology related. Due to the fact that lymphoedema can have multiple causes the care pathway can be complex. The main areas of referral into a comprehensive lymphoedema service are oncology, vascular, chronic oedema and cellulitis. These basic pathways are depicted in **(Figure 9)** but the details of each care pathway will need to be decided in conjunction with the development of the standards of care.

Figure 9: Lymphoedema Care Pathway



4.3. Conclusion

There are recognised international standards of care for lymphoedema and lipoedema services. It is evident that in all areas of essential lymphoedema/lipoedema care there are gaps when comparing current services to best practice in Ireland. A Model of Care is essential to have a co-ordinated, integrated approach and to provide up to date, effective and efficient services.

The recommendations for prevention and early detection will ensure that patients are screened for high risk and receive education for prevention and early detection. This will improve quality of life for patients and will be essential for future management of a condition where its prevalence is increasing.

The assessment and treatment recommendations will ensure a regional specialist lymphoedema service is provided with maintenance treatment in local primary care networks with clear pathways and access to MD support services. There will be standardised assessment, treatment and audit to ensure quality services and patient safety. A Minimum Data Set will be collected as routine and will provide information on service demand and will be essential for planning purposes. The introduction of structured, widespread lymphoedema services will reduce the incidence of cellulitis and reoccurrence with potential cost savings for the HSE.

A comprehensive education programme will ensure heightened awareness and prevention information for all clinicians. It will also assist with effective screening and early detection of lymphoedema/lipoedema in high risk patient cohorts and will result in competent and qualified lymphoedema therapists.

A multifaceted approach is needed for this Model of Care and will be described in the next chapter.

5. The Lymphoedema/Lipoedema Model of Care

The aim of this chapter is to describe the future structure of lymphoedema/lipoedema services including how the services will work, who will provide the services, where they will be provided and the governance structure required to ensure the services provide optimum care. The Working Group determined that the services are best placed in the primary care/community setting in keeping with the Sláintecare aim of moving appropriate services out of acute centres and delivering care close to home. Specialist Lymphoedema Clinics (SLCs) should be established in primary care settings with in-reach services to acute hospitals as required e.g. oncology, vascular services and palliative care. These SLCs will act as a regional centre of expertise for the management and treatment of lymphoedema, development of services locally and co-ordination of patient care with other support services. Maintenance and prevention services will be carried out in the wider community services with links to the SLC. High risk patients in acute oncology, vascular and frail elderly care services will be targeted for specific attention and assessment across acute and community services.

5.1. Overview of the Model of Care

The recommended Model of Care for lymphoedema/lipoedema is a 'hub-and-spoke' model (**Figure 10**). The 'hubs' will be specialist lymphoedema clinics to provide assessment and intensive treatment with appropriately trained therapists, supported by access to appropriate specialist support services based in either the acute or community services. There will be one SLC in each CHO area. The 'spokes' will provide maintenance treatment and support delivered by existing therapists in primary care settings. The lymphoedema/lipoedema services will be integrated with therapists having opportunities to work cross-site with all services in primary/community care and in-reach services in acute hospitals. All staff will be appropriately trained within the training levels 1, 2 and 3, as previously described in **Table 12**.

The main objectives of the Model of Care are to:

- Have an integrated Model of Care based on guidelines, evidence-based medicine and documented best practice to which all health professionals will adhere.
- Ensure that the patient is the centre of the care process and has an active role in their self-management.
- Ensure patients are diagnosed as early as possible to ensure best outcomes are achieved.
- Minimise the use of acute services and focus on the management of lymphoedema/lipoedema conditions emphasising primary care, home care and self-care.
- Utilise healthcare staff in coaching/mentoring roles.
- Use clinimetrics, standardised and validated measuring methods and questionnaires to monitor the effects of treatment programmes.
- Have effective, digital electronic patient files to ensure communication between all healthcare staff and patients.

5.2. The Structure of the Model of Care

Within this 'hub & spoke' model the 'hub' will be a 'Specialist Lymphoedema Clinic' (SLC) located in an appropriate primary care location to provide assessment for all patients with lymphoedema/lipoedema and treatment for patients with moderate to severe lymphoedema/lipoedema. The 'spokes' will be provided within the existing Primary Care Team and Primary Care Network services and will comprise of Level 2 trained therapists who will provide maintenance services in local primary care centres or other community locations. The SLC will have established links with acute hospitals and will provide support and clinical advice to staff in the management of patients with oncology, palliative care, cellulitis and other lymphoedema related conditions (**Figure 9**). The SLC will also provide mentoring, training and advice to the Level 2 trained therapists operating in primary and community care locations. As previously emphasised, a key component of the Model of Care is extensive Level 1 education and awareness training for all health care staff. This widespread awareness within health communities will assist with the prevention, early detection and subsequent referral to appropriate SLC services.

5.2.1. The Specialist Lymphoedema Clinic (SLC) Level 3

There will be one SLC for approximately 500,000 people serving each CHO / HG. SLC personnel may be required to provide outreach services in different primary care locations to facilitate better patient access, including domiciliary visits, where necessary, and the SLC will also actively participate in shared care.

Each SLC will have a team of lymphoedema therapists trained to Level 3 standard, the number of therapists will depend on the population needs for services in each CHO **Table 15**. The SLCs will have established links with the local acute hospitals and primary care services in its area to directly provide and support the provision of the full range of lymphoedema services for the CHO area.

There will be one Lead Lymphoedema Therapist, trained to Level 3, at clinical specialist level. They will, in addition to providing direct clinical services to patients, lead the SLC team, work on service development, ensure high quality services are provided, oversee staff supervision and training, and maintain data collection, audit and research. Drawing from the experience of other jurisdictions, notably Wales, the recruitment and engagement of multi-task attendants helps to improve the efficient running of specialist lymphoedema clinics. The multi-task attendant will provide a range of supportive ancillary duties to improve the patient experience and efficient and effective running of the SLC. Such duties will include managing and scheduling all patient appointments, assisting patients in preparation for treatment (dressing and undressing), general advice to patients in relation to compression garments, stock management, etc. The employment of multi-task attendants is more cost effective, will allow for more therapist-to-patient time and allow for increased patient throughput. Extrapolating from the international experience to date it is recommended that 1 WTE multitask attendant be employed for each SLC.

The location of each SLC will vary, according to existing CHO services, patient population density and geography with patient access being the priority. The SLC will have referral pathways to necessary multi-disciplinary support services, e.g. dietician, vascular consultant, oncologist, for complex patients. The pathways will vary depending on existing staff and service configurations in each CHO and the associated acute hospitals.

5.2.2. Lymphoedema/Lipoedema primary care delivered services Level 2

The primary care elements of the lymphoedema/lipoedema Model of Care will be delivered by HSCPs and nursing staff, trained to education Level 2. These services will be based in primary care and will be accessible to patients in their local community across each CHO. These will be delivered by core primary care team staff who have undergone the training and will provide maintenance services to patients who have been treated and stabilised in the SLC. These core staff will also support best practice implementation in relation to management of chronic oedema. These services will have established links with patient support groups such as Lymphoedema Ireland and local cancer care support groups to enable patients to best manage their condition independently.

The number of primary care HSCP and nursing staff trained to Level 2 will depend on the population demand in each CHO and with due regard to ensure that patients will be able to access their services locally. These services

will have established links into the SLC in accordance with the lymphoedema care pathway and will have access to shared care with acute services where required.

5.2.3. Wider health system Level 1

In the high risk areas for lymphoedema such as oncology and older peoples' services, healthcare professionals will be educated in screening, prevention, early detection and awareness. All identified high risk patients will access the SLC via a rapid referral care pathway. These service areas will have established links into the SLC as detailed in the lymphoedema care pathway (Figure 9).

The structure of the Model of Care in each CHO is depicted in (Figure 10) and summarised in Table 13

Figure 10: Structure of the Lymphoedema Model of Care

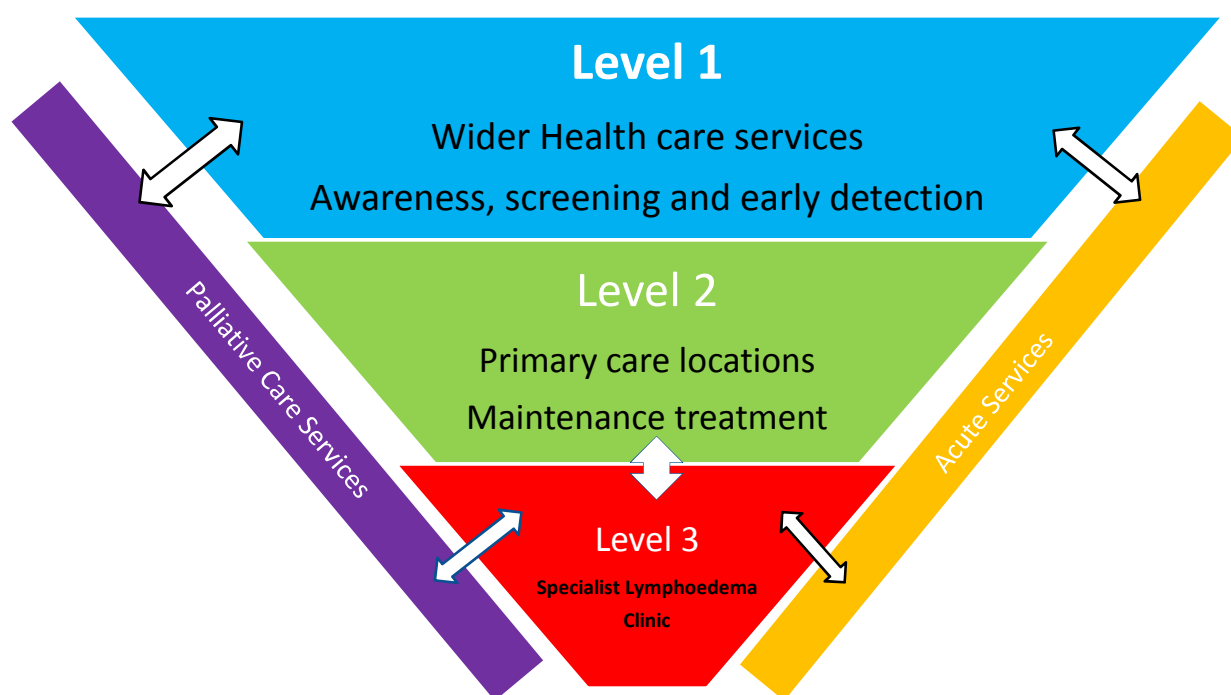


Table 13: Summary of the Model of Care Structure, Staffing and Education Levels

Location	Staff	Number of staff	Service/Role in MOC	Education level
Specialist Lymphoedema Clinic in community locations	Lead Lymphoedema Therapist	9 WTE	Service development Data collection and audit Quality improvement Assessment Intensive and modified treatment Provide education for Levels 1 and 2	Level 3
	Lymphoedema Therapists	47.3 WTE	Assessment Intensive and modified treatment Provide education for Levels 1 and 2	
	Multitask attendant	9 WTE	Assist the therapist in patient care e.g. Preparing patients for treatment Clerical duties Stock management Appointment scheduling and management	

Primary Care locations	Existing therapy staff and nursing staff	2 per CHN (Each working .06 of their WTE)	Maintenance treatment	Level 2
Wider Healthcare services	GP		Diagnosis, screening and referral into the care pathway	Level 1 - GP
	Healthcare staff in high risk areas		Screening, basic preventative care and referral into the care pathway	Level 1 - high risk
	All HSE staff		Awareness, basic preventative care and referral into the care pathway	Level 1

5.3. Staffing requirement for Optimal Care

Implementing the model of care will require additional staffing levels. The staffing levels required can be calculated based on the 12,380 projected number of lymphoedema patients (Section 2.4) and the number of patients each therapist can effectively manage annually. The WG has referred to UK experiences and the Kaiser Permanente chronic conditions model (referenced earlier in **Figure 3**) in estimating the overall staffing requirement.

The British Lymphoedema Society accepted treatment and support hours required annually per patient is; 2 hours for maintenance treatment, 20 hours for modified intensive and 60 hours for intensive treatment **Table 14**. In applying the Kaiser Permanente chronic conditions model across a typical range of lymphoedema patients the number of estimated patients at each level of treatment can be calculated. The total required hours for delivering the MOC to 12,380 patients is 141,132 hours per year. The SLC will need to provide 123,800 hours of intensive (74,280 hours) and modified intensive treatment (49,520 hours). 17,332 projected hours are required for maintenance treatment to be carried out by existing primary care staff.

Table 14: Time required to provide a Lymphoedema/Lipoedema service annually

Treatment Levels % Patients	No. of patients	Number of annual hours required per patient	Total annual hours	Provided by
Maintenance 70%	8,666	2	17,332	Existing Primary Care Staff
Modified intensive 20%	2,476	20	49,520	SLC
Intensive 10%	1,238	60	74,280	SLC
Total	12,380		141,132	

The introduction of screening and early diagnosis would potentially further reduce the number of complex patients presenting in the future, thus affording more capacity for the therapists.

Based on international studies (Wales, 2006) a lymphoedema therapist will be able to effectively manage 150 lymphoedema/lipoedema patients and up to **220 patients per year with support staff**. This includes all levels of complexity, providing the full range of treatment, prevention and education.

When applied to the Irish context, there will be a need for 56.2 WTEs **Table 15**. As recommended in Section 5.2.1 each of the 9 SLCs will employ a multi-task attendant, resulting in an overall WTE requirement of 65.2 WTEs **Table 15**.

Table 15: Overall projected Staffing requirements per CHO to implement the Lymphoedema Model of Care

CHO / population	Potential patients (2.6 per 1,000)	Therapist WTE (220 patients per therapist)	Multi-task Attendant	Total WTEs required
CHO 1/391,281	1,017	4.6	1	5.6
CHO 2/453,109	1,178	5.4	1	6.4
CHO 3/384,998	1,001	4.5	1	5.5
CHO 4/690,575	1,795	8.2	1	9.2
CHO 5/510,333	1,327	6.0	1	7.0
CHO 6/393,239	1022	4.6	1	5.6
CHO 7/697,644	1,814	8.3	1	9.3
CHO 8/619,281	1,610	7.3	1	8.3
CHO 9/621,405	1,616	7.3	1	8.3
	12,380	56.2	9	65.2

As established from the survey conducted there are 11.1 WTEs (including palliative care services (2.4 WTEs)) working in lymphoedema services in the country (n=70 people) which would equate to a net additional need for **45.1 WTE** therapists (56.2 minus 11.1). This is in addition to the **9** multi-task attendants required to provide comprehensive services based on population demand. The recruitment and filling of these positions would allow for the successful implementation of the MOC for the estimated 12,380 lymphoedema patients.

As already outlined there are 70 trained lymphoedema staff in the country whose skills are not fully utilised and this presents opportunities to employ the additional 45.1 therapists needed. From feedback received as part of the information gathering exercise and the consultation process it would appear that there is strong interest for such positions within the trained therapist cohort who are very passionate, patient-centred and highly motivated about this area of their work.

The job descriptions and roles should be developed as part of an Implementation Plan in association with HSE Human Resources personnel and utilising the BLS National Tariff Advisory Document and should serve as a solid reference in drafting the job descriptions and roles. The BLS National Tariff Advisory Document is included in **(Appendix 3)**.

WTE deficit per CHO to meet optimal staffing levels

All CHO's have some Level 3 trained staff in their reported current services. The existing therapy staff and the projected WTE deficit per CHO to implement the Model of Care are detailed below **Table 16**. The Model of Care incorporates the use of multi-task attendants, 1 for each SLC. These do not currently exist in any CHO service and accordingly, there will be a requirement for 1 for each SLC.

Table 16: Existing WTE deficit per CHO (2017) to meet Lymphoedema MoC Staffing requirement

CHO	Therapist WTEs required (220 patients/therapist)	Existing Therapist WTEs (2017)	Therapist WTE Deficit per CHO	Multi-task Attendant WTEs needed	Existing Multi-task Attendants WTEs	Multi-task WTE Deficit per CHO
CHO 1	4.6	1.7	2.9	1	0	1
CHO 2	5.4	1.2	4.2	1	0	1
CHO 3	4.5	1.2	3.3	1	0	1
CHO 4	8.2	1.1	7.1	1	0	1
CHO 5	6.0	1	5.0	1	0	1
CHO 6	4.6	.2	4.4	1	0	1
CHO 7	8.3	*1.9	6.4	1	0	1
CHO 8	7.3	.9	6.4	1	0	1
CHO 9	7.3	1.9	5.4	1	0	1
Total	56.2	11.1	45.1	9	0	9

*One therapist not included as not certified at level 3 and providing maintenance treatment only.

A plan will be needed for each CHO to determine the composition of future services, sites and skill mix to implement the MOC at local level. The WTEs needed for implementation of services will change according to the expected increased surge in demand due to increased awareness and consequent increases in referrals as the services develop. This will need to be planned and reference to the Northern Ireland experience will provide valuable learning for implementation.

Benchmarking

The Working Group, as part of its assessment of staffing need, examined the existing staffing levels in the UK. The data for England is not comparable as, unlike its other UK country counterparts, it does not have a standard nationwide developed lymphoedema service. Table 17 below sets out the comparative benchmarked staffing figures for Scotland, Ireland, Wales and Northern Ireland. It is evident that Ireland lags well behind.

Table 17: Benchmark of current Irish lymphoedema staffing with comparative UK countries

Country	Population	Lymphoedema Prevalence (2.6/ 1,000)	Current Lymphoedema Therapist Staff	Assistants	Average number of Lymphoedema Patients per Therapist
Wales	3.063m	7964	27.3	12	291
Scotland	5.295m	13,767	36	0	382
Northern Ireland	1.810m	4708	10.75	3.8	473
Ireland	4.761m	12,380	11.1	0	1,115

Staffing costs for providing optimal care

The introduction of the Model of Care to provide optimal lymphoedema services will, as outlined above, require 45.1 additional WTEs to support the 11.1 WTEs currently working in the services. This will include the 9 Lead Therapists, one for each SLC, who will work at clinical specialist level (as outlined in 5.2.1).

As previously outlined there are adequate numbers of trained lymphoedema therapists available to take up full-time positions in the SLCs. In the event of this happening there would be implications for the other non-lymphoedema work that these staff are currently engaged on. Either way, the overall health system will require the funding for 45.1 additional therapy WTEs and 9 multi-task attendant WTEs, if the MOC is to be implemented. **Table 18** sets out the estimated net cost per CHO to implement the Model of Care. This includes the net staffing cost (recommended therapists staffing levels less existing WTE levels) and 1 new multi-task attendant post per SLC.

Table 18: Additional WTE and Cost per CHO to meet optimum staffing levels

CHO	Lead Therapist per CHO WTE (€74,401)	Therapist per CHO WTE (€67,781)	Multi-task Attendant per CHO WTE (€37,937)	Lead Therapist Costs	Therapist Costs	Multi-task Attendant Costs	Total staffing costs per CHO
CHO 1	1	1.9	1	74,401	128,783	37,937	203,183
CHO 2	1	3.2	1	74,401	216,897	37,937	291,300
CHO 3	1	2.3	1	74,401	155,895	37,937	268,234
CHO 4	1	6.1	1	74,401	413,461	37,937	525,802
CHO 5	1	4.0	1	74,401	271,122	37,937	383,462
CHO 6	1	3.4	1	74,401	230,454	37,937	342,793
CHO 7	1	5.4	1	74,401	366,015	37,937	478,355
CHO 8	1	5.4	1	74,401	366,015	37,937	478,355
CHO 9	1	4.4	1	74,401	298,234	37,937	410,570
Total	9	36.1	9	669,609	2,446,880	341,435	3,457,927

A full breakdown of staffing costs based on salary scales at 1st January 2018 is attached at Appendix 5.

Non-pay costs for providing Optimal Care

While there will be some once-off non-pay costs in accommodating SLCs the principal non-pay costs will be due to introducing the recommendation of providing 2 compression garments, for eligible patients, every 6 months, currently issued at a rate of 2 per year in some areas. The spend for the provision of compression garments in 2016 was €800,000. This data includes garments for vascular and lymphoedema patients and it is not possible to differentiate between these at this time. Based on the current under-usage of compression garments in the management of lymphoedema we can estimate that this cost will increase with the introduction of the Model of Care and associated better management of the condition. In the absence of good data it is not possible to predict, based on the 12,380 patients, what the costs of compression garments might be as data on multi-limb needs, custom-made/off-the-shelf ratios would be needed. Given that Ireland's purchase prices are comparable to Northern Ireland, it is reasonable to use their expenditure as a benchmark. In Northern Ireland the current annual cost for lymphoedema compression garments is £1M which would equate to approximately €3M for the population in Ireland. As there are patients who must self-pay, the working group estimates that the cost would

be closer to €2M and there will also be some cost savings with the improved procurement process. The current spend is €800,000 and with an overall increase the annual cost will be estimated to be €1.2M.

The capital and other equipment needed to support the introduction of the Model of Care are outlined in **(Tables 19 & 20)** below.

Accommodation

The nine SLC's will be based in primary care and integrated with hospital services and, ideally, placed in primary care centres with other services available. Each SLC will have an average of 4-6 staff; the clinical lymphoedema specialist, 3-4 lymphoedema therapists and one multi-task attendant. 1 therapist will link with acute services and primary care services to provide education and support leaving an average of 3-4 therapists in the SLC with a requirement of 3-4 treatment rooms per centre. The treatment rooms will need to have full privacy, i.e. not curtained, as patients are often undressed. The Lead Therapist would require an office for administration. Accommodation requirements are detailed in **Table 19** and will vary in each CHO depending on the existing infrastructure.

Table 19: Accommodation for the SCL service per CHO

Type of room	No. of rooms
Clinic room	3-4
Storage room	1
Male/female toilets/disabled	1
Waiting area	1
Reception	1
Office	1

The equipment needed for the SLC's will vary depending on the location of the service with most multidisciplinary services having the equipment required as existing stock. A generic list is provided in **Table 20** and will need to be agreed with each CHO, for the purposes of this report an estimated €5,000 per clinic is included in the projected costs. There are minimum requirements for the associated Primary Care locations to provide maintenance treatment for lymphoedema patients.

Table 20: Equipment requirements for the Model of Care for each SLC

Equipment	Required per Specialist Lymphoedema Clinic	Costs	
Adjustable clinical couch	4 at least 1 for bariatric patients	€9,000	
Bioimpedence/moisture meter for detection of stage 0	1, cost approx.	€10,000	
Limb measuring tapes/method for calculating limb volume (specialist calculator/computer program)	Yes	€5,000 (average clinic cost)	
Compression garment measuring equipment (tapes/measuring boards)	Yes		
Doppler equipment and sphygmomanometer	1		
Camera	1		
Skin care supplies, including dressings	Yes		
Bandaging/foam/padding/tape	Yes		
Patient support wedges	4		
Wheeled stool	4		
IT Hard ware	2 desk top 1 laptop 1 printer		2,320
Total			€26,320

NB In larger services or those wishing to participate in research, this list may include equipment for bioimpedance analysis, perometry and tonometry. Equipment should comply with guidelines for manual handling and infection control.

Estimated cost for IT software to use in conjunction with the Primary Care Management System has been estimated to be approx. €200,000.

Other equipment

- Telephone
- Computer, printer, stationery
- Desk, chair, lockable filing cabinet

5.4. National Lymphoedema Implementation Group

As outlined in the Model of Care effective lymphoedema management involves cross-site service provision, multidisciplinary and multiple medical speciality involvement e.g. oncology, dermatology and vascular. Communication with, and the involvement of all principal stakeholders, will be key to the successful implementation of the Model of Care. The establishment of an overarching National Lymphoedema Implementation Group is recommended to oversee and co-ordinate the implementation of the Model of Care in Ireland. The Group will bring representation from all stakeholders and disciplines, including patient representatives, to provide a cohesive, involved and measured approach to the introduction of a new system for the effective management of lymphoedema, the Model of Care.

Patient representation will be sought from representative groups such as Lymphoedema Ireland (LI) and the Irish Cancer Society.

It is recommended that a Clinical Project Manager be appointed to co-ordinate the work of the Implementation Group and to oversee the implementation of the Group’s recommendations. The Clinical Project Manager should be supported in his/her work by the appointment of a National Clinical Lead, with an interest in lymphoedema/lipoedema to work one day a week on the programme. He/she will provide expert clinical input into the implementation process, including the establishment of national standards of care and provide a source of expert clinical advice and oversight to all work of the Implementation Group. A priority action for successful implementation of the MOC would be the early recruitment of the 9 Lead Lymphoedema Therapists, one for each CHO area. It is recommended that these be recruited initially with the Clinical Project Manager and National Clinical Lead, to lead out on the co-ordination and planning for CHO implementation of the MOC and also to participate, as required, in the National Lymphoedema Implementation Group’s work. Projected cost details for implementation are detailed in (Table 21) below.

The aims of the National Lymphoedema Implementation Group will be to;

- Oversee the planning and implementation of the Model of Care.
- Develop lymphoedema standards of care for Ireland.
- Facilitate and support the implementation of the Model of Care in each CHO.
- Develop a standard education plan to be implemented nationally.
- Review audits and outcome measures to ensure goals and targets are met to drive quality improvement and develop a sustainable lymphoedema services infrastructure for services.

Table 21: WTE costs for the initial implementation phase of the Model of Care

Implementation Team		
Clinical Project Manager (Grade VIII) (salary scale 1/1/2018)	1	€87,093

Consultant x 1 day per week (based on Type A contract type - revised salary scale 1/4/2018 - 4th point)	0.4	€73,000
Total		€160,093

Note the above costs do not include the 9 Lead Therapist recommended for the implementation. These costs are set out in Table 18.

5.5. Quality improvement

Irish standards of care need to be established for lymphoedema and lipoedema services as part of an overall approach to introducing a quality improvement process for the care of lymphoedema/lipoedema patients. The standards are necessary to ensure evidence based practice, standardisation of approach to avoid duplication, provide guidance for audit, reduce variation in clinical practice and improve methodological rigour. The standards will include policies, procedures and protocols and will encompass care pathways, clinical decision tools, bundles of care and flow charts in line with the Model of Care. The standards will be in line with the National Clinical Effectiveness Committee (NCEC) guidelines and will ensure compliance with the National Standards for Safer Better Healthcare (HIQA, 2012).

An Expert Clinical Group should be formed, chaired by the National Clinical Lead, to agree such standards, referencing current research, international standards and guidelines. Clinical audit will be an on-going feature of the future service to measure services against the new standards of care and identify areas of excellence or concern and recommend appropriate changes as part of the quality improvement process for patient care.

Quality improvement processes will include the introduction of local audit of patient outcomes, review of any complaints, regular monitoring of waiting times, patient satisfaction reviews and any other processes identified in the standards of care.

Local services will be required to submit agreed standardised data for review and will also be mandated to act upon recommended improvements. National fora will be created for the dissemination of learning to colleagues. Individual CHO's will be responsible for the delivery of services locally and the Chief Officer of each CHO will retain overall accountability for lymphoedema services.

5.6. Governance of the Model of Care

The HSE's Governance for Quality and Safety Framework in healthcare is underpinned by a suite of ten guiding principles. The Model of Care takes cognisance of these principles. The HSE Clinical Strategy and Programmes Division, in collaboration with the Quality Improvement Division, developed a Guide for Quality and Safety Governance in 2014 (**Figure 11**). The success of a Model of Care is dependent on incorporating sound quality and safety governance arrangements. This Model of Care has been proofed against these ten guiding principles.

Figure 11: Guiding principles for quality and safety



Having implemented the Model of Care the CHO Chief Officers will be responsible and accountable for the delivery of integrated lymphoedema services in their respective CHO areas in keeping with the HSE's annual Performance and Accountability Framework.

Responsibility for day to day operational management of these services will be assigned to the Head of Service, Primary Care in each CHO. The Lead Therapist in the SLC should report operationally to the Head of Service Primary Care, or designate, and clinically to the Head of Discipline/Director of Public Health Nursing (DPHN) or other Lead Clinician as determined via the CHO operating model. The Lead Therapist will manage the performance of all assigned staff, including those in outreach services, as well as the collective lymphoedema service team performance ensuring the achievement of service targets, key performance indicators and compliance with the National Standards for Safer Better Healthcare etc. As the model and associated organisation structures envisaged in the CHO Report evolve and are implemented there may be changes in these reporting relationships.

Therapists will be responsible to maintain their registration with the relevant registration body and will, in collaboration with the Lead Therapist, maintain their own professional development.

The Lead Therapist will participate in the CHO and Acute Services Quality and Safety Committees and other committees as relevant to ensure comprehensive and integrated care. In collaboration with the DPHN / Head of Discipline, he/she will be responsible to ensure that structured clinical audit is undertaken regularly and that any arising shortcomings be addressed.

5.7. Information and Technology

An up to date ICT system is needed to improve the effectiveness and efficiency of staff and the overall service and also to enhance patients' experiences of the management of their condition.

- A shared electronic healthcare record will be essential for communication between the team and to facilitate cross-site integration.
- Data collection can be time consuming and the development of a structured data base and agreed minimum data set will help to limit this. It is essential across all sites to ensure consistent and collaborative data collection and allow national analysis of the services. Information technology should facilitate ease of data presentation and entry for therapists and allow access to input at different locations. This will be integrated with the Primary Care Management System, currently in planning phase, with additional software to encompass clinical data and outcomes.
- New developments in health technologies in relation to chronic disease management can be used in the self-management of lymphoedema. These include self-measurement and monitoring, promotion of

adherence and patient activation and assistive technologies. These should all be explored by the Expert Clinical Group in their work on developing the standards of care.

Resources

The implementation of the Model of Care will need to be resourced at CHO level with the appointment or reassignment of staff. The Implementation Group will also need to be resourced to oversee the Model of Care implementation. A detailed plan for resources will need to be developed with each CHO Chief Officer, as part of the implementation roll out. **Table 22** below sets out a summary of estimated overall costs, pay and non-pay, for the successful implementation of the Model of Care. As previously outlined, the cost-savings from hospital avoidance i.e. €11.8M alone more than justifies the €5.2M expenditure needed.

Table 22: Overall additional resources required both pay and non-pay per annum.

Resources	WTE	Pay €	Non-Pay €	Total Cost €
Lymphoedema Therapist	36.1	€2,244,240	€202,640	€2,446,879
Multi Task Assistant	9	€313,159	€28,276	€341,435
Lead Therapist	9	€614,157	€55,454	€669,611
Clinical Project Manager	1	€79,881	€7,212	€87,093
Consultant (2 days p.w.)	.4	€66,901	€6,099	€73,000
Compression Garments			€1,200,000	€1,200,000
Early detection equipment			€90,000	€90,000
Bariatric Beds			€56,000	€56,000
Other Clinic costs*			€45,000	€45,000
IT hard ware			€20,880	€20,880
IT costs (estimated)			€200,000	€200,000
TOTAL	56.4	€3,318,338	€1,911,561	€5,229,898

**These costs are an estimate per clinic from Table 20.*

5.8. Conclusion

This proposed MOC is based on international best practice and recommendations to provide a patient centred, efficient, standardised lymphoedema/lipoedema service. The structure is based on a 'hub' and 'spoke' model with Specialist Lymphoedema Clinics, SLCs located in the community, with in-reach to acute services and palliative care. These clinics will provide assessment and intensive/modified treatment to all lymphoedema patients, regardless of aetiology. The staff in the SLC will include a Lead Therapist, Lymphoedema Therapists and a multitask attendant. Services in primary care will provide maintenance treatment by existing staff with appropriate training.

To provide comprehensive services there is a requirement for 56.2 therapists and there are currently 11.1 WTEs in the HSE. This is an additional requirement of 45.1 therapists plus 9 multi-task attendants. There is also a need for a National Clinical Lead, a Consultant with an interest in lymphoedema to work 2 days per week. This staffing requirement is in line with international benchmarking.

The overall annual cost of the MOC is approximately €5.2M and this will be off-set by the potential savings of €13.9M as detailed in **Table 23**.

To successfully implement the MOC an implementation plan is needed with a Clinical Project Manager and National Clinical Lead input. A Lead Therapist from each CHO (9) is required to oversee local implementation of the MOC, work with all stakeholders and lead the service locally. Each CHO has varying challenges to implementation depending on existing services and geography.

It is essential that services are standardised and equitable and that a robust quality improvement programme and governance structure is in place. This will ensure that the Model of Care encompasses patient safety, efficiency and value for money to fulfil the aims and objectives of the Working Group.

This recommended model of care will have benefits for patients, staff and the HSE which will be described in the Chapter 6.

6. The impact of providing Optimal Care

6.1. Impact on the patient

The following is a summary of the anticipated impact of implementing the Model of Care and providing optimal lymphoedema/lipoedema care to all patients.

- Prevention strategies that will reduce the risk of developing lymphoedema for patients.
- Equal access for all lymphoedema/lipoedema patients regardless of the aetiology of the condition.
- Reduced waiting times and early diagnosis will diminish the impact of lymphoedema/lipoedema on quality of life for patients.
- Access to standardised intensive treatment in a specialised clinic will ensure best practice and positive outcomes.
- Maintenance treatment in the local primary care locations will reduce travel time for patients.
- Education and support in their local community will empower patients to self-manage these chronic conditions.
- Patient satisfaction will improve with enhanced access and treatment.
- Treatment will reduce the severity of lymphoedema/lipoedema and improve quality of life.

It should be noted that the Lymphoedema Network Northern Ireland (LNNI) was set up in 2008 and the impact of the service to date includes:

LNNI

- Reduction in waiting times from 2 years to 9 weeks for chronic and 1 week for acute referrals
- Equal access with 54% of referred patients being non-cancer related
- Optimal treatment was offered to 95% of the patients
- There was an 80% patient satisfaction rate.

The MOC proposed for Ireland is in line with the LNNI model and anticipated outcomes can be expected if successfully implemented.

6.2. Impact on staff providing the services

Treating lymphoedema/lipoedema is very physical work and can lead to early burn out and isolation for staff involved. This has been experienced by Irish therapists working in lymphoedema patient services (Murray, 2010) and has been reflected as part of the consultation process in the compilation of this report. A team approach will allow for better skill mix and peer support and will consequently help to ensure that the physical and other

workloads are shared. This will also improve cover for all leave and improve staff retention and succession planning.

The establishment of a clinical forum will allow for dissemination of information, including the discussion of and learning from complex cases so that all therapists are informed and up to date with any recommended changes in practice. The Model of Care model aligns with the strategic priorities of *Healthy Ireland National Implementation Plan 2015-2017* to improve staff health and wellbeing.

The structured approach to providing services as outlined in the Model of Care will create opportunities for career progression and for employment in non-acute facilities. It will also offer multi-site (including acute) work experiences.

6.3. Impact on efficiency and value for money

Where implemented, a comprehensive lymphoedema service has produced efficiencies and cost savings in many areas, (detailed later on), including the following:

1. Reduction in the prevalence and reoccurrence of cellulitis with reduced admissions to acute hospitals.
2. Education in the management of chronic oedema has led to reduced GP visits, reduced nursing time and reduced cost of dressings.
3. Screening and early detection has reduced the need for high cost intensive treatment.
4. Reduction in time off work due to improved QOL with reduced associated disability benefits. In a review of breast cancer patients with lymphoedema, patients with sub-clinical or mild lymphoedema had an average of 1.4 sick leave days per year compared to 8.1 days for patients with moderate to severe lymphoedema. (Boyages, 2016)

The economic benefits of setting up a comprehensive lymphoedema service have been demonstrated in other countries as follows:

- A report by Macmillan Cancer Support, 2011, showed that for every £1 spent on lymphoedema services £100 was saved from reduced hospital admissions.
- A recent study in London evaluated the impact of a community based lymphoedema service on 312 patients. The incidence of cellulitis dropped from 41.5/ 100 patient years at baseline to **zero at 6-12 months**. There was a corresponding **65%** reduction in six monthly community health care costs from £50,171 per 100 patients to £17,618 between 6 and 12 months. (Moffatt, 2017)
- The City and Hackney CCG demonstrated a **94%** reduction in episodes of cellulitis and an **87%** reduction in cellulitis-related hospital admissions following the introduction of a community based lymphoedema service (O'Neill, 2015).
- A chronic oedema service set up in Wales in 2016 involved 426 patients with chronic oedema of which 97 were co-treated by lymphoedema therapists for 3 months (Thomas, 2017). They demonstrated:
 - **54%** reduction in district nurse visits, saving £62,270, a mean of €641 per patient
 - **63%** reduction in dressing costs, saving £32,752, a mean of £337 per patient

To equate this to the Irish context, from the prevalence data (Section 2.4.4) it can be estimated that there are 7,479 patients with leg ulcers associated with chronic oedema which would give potential savings of €4.7M in PHN visits and €2.5M in reduced dressings costs by introducing a similar programme.

- An American cost comparison study demonstrated that early treatment of oncology related lymphoedema cost **80%** less than treatment when the patient was symptomatic (Stout, 2012)
- Cost savings can be made through the reduced use of TAS and the CBD when the Model of Care is fully implemented. Until then there will still be a requirement for these services and also an on-going need for surgery related to lymphoedema.

Table 23: Summary of costs and savings

Annual cost and savings of providing community lymphoedema services		Cost	Savings
Annual Cost of Providing Community Lymphoedema Services			
Pay Costs	Staffing	€3,318,338	
Non-pay costs	Equipment, Compression garments, IT, staff non-pay costs, etc.	€1,911,561	
Total Costs – Pay & Non-Pay		€5,229,899	
Potential Savings annually due to the introduction of lymphoedema services			
Reduced hospital admissions due to cellulitis for lymphoedema/chronic oedema patients			€11.8 M
Reduced use of TAS (Based on an average over the last 5 years)			€23,000
Reduced cost of dressings for patients with leg ulcers and chronic oedema (Based on Thomas, 2017)			€2.5M
Reduced PHN visits for patients with leg ulcers and chronic oedema (Based on Thomas, 2017)			€4.7M
Reduced private therapist costs (Based on 2016 hours and cost)			€122,640
Total savings			€19,145,640
Net savings			€13,915,742

6.4. Conclusion

The model of Care will provide significant benefits to patients, staff and the HSE. A projected budget of €5.2M will provide a comprehensive service for patients that will reduce the risk and severity of the condition and deliver better, quality-assured services for complex patients, leading to improved quality of life. It will also lead to improved staff satisfaction and retention and sustainability of services. It will, potentially, save up to €13.9M annually by reducing incidence and reoccurrence of cellulitis requiring hospital admissions, reduced usage of dressings and antibiotics, reduced use of contracted lymphoedema services and treatment abroad scheme services. These savings will be gradual as the services develop but will be demonstrable and maintainable with the

proposed model of care. For every €1M spent there will be savings of €2.6M every year when services are established.

This is an ideal opportunity to invest to save money to provide a sustainable, comprehensive lymphoedema/lipoedema service which will significantly improve patient's quality of life.

7. Recommendations

The recommendations are extensive but many are easily achievable with integration of current services and minimal resources in some areas e.g. education and screening.

The implementation plan will action the recommendations with set milestones and goals to safeguard sustainability. The plan will have a phased in approach to staffing as services develop and current services are integrated.

As services develop and care moves more to the community a skill mix review will be required to look at more support in primary care locations with less reliance on the SLC.

The key recommendations for the implementation of the Model of Care are summarised below:

Lymphoedema prevention and early detection recommendations:

1. Risk of lymphoedema should be included in the pre-operative consent form for all surgeries that involve the lymphatic system.
2. Patients should have access to information on lymphoedema risk, prevention and self-detection.
3. Development of prevention awareness and screening tools in all high risk areas e.g. oncology units, vascular departments, older people service facilities.
4. Development of early detection protocol, stage 0, for patients assessed as high risk with referral pathway for rapid assessment.
5. Genetic counselling to be made available for patients with primary lymphoedema.

Assessment recommendations:

6. One Specialist Lymphoedema Clinic to be established in each CHO, in a community location for assessment, intensive treatment and education for all types of lymphoedema and lipoedema.
7. Acceptable assessment waiting times should be identified and met when the standards for lymphoedema are agreed.
8. Clear referral pathway from the SLC into identified multidisciplinary support services should be documented.
9. Standardised assessment and care plan tool with appropriate IT enabled software, needs to be procured and deployed.
10. Minimum data set to be recorded on each patient should be agreed by an Expert Group and introduced.
11. Recognised standard outcome measures should be agreed and introduced in all lymphoedema services.
12. One SLC will provide paediatric lymphoedema assessment services as a sub-speciality.
13. Lymphoedema assessment will be introduced into the cellulitis care pathways for appropriate patients.

Treatment Recommendations:

14. An agreed lymphoedema algorithm will be introduced to ensure standardised best practice is followed.
15. One SLC will provide specialist paediatric lymphoedema services.
16. All lymphoedema specialist clinics should offer daily intensive treatment for oncology and non-oncology related lymphoedema.
17. Guidelines for the prescription of compression garments need to be agreed and introduced.
18. Patients should be reviewed at least every 6 months and measured for compression garments in their local community lymphoedema services.
19. Eligible patients should be provided with 2 garments every 6 months.
20. Additional funding should be made available for eligible patients for garments every 6 months.
21. SLCs should link with local patient support groups e.g. Lymphoedema Ireland, to support lymphoedema patients in managing their condition.
22. Guidelines for the management of obesity related lymphoedema should be agreed and introduced.
23. SLCs should be appropriately equipped with access to bariatric equipment, electric beds, measuring equipment, IT data systems etc.
24. Psychosocial supports, working with local support groups should be available to patients.
25. Self-management innovations such as eLearning, educational videos and apps should be developed.

Education Recommendations:

26. Devise and implement a national education plan for all stakeholders, including patients, lymphoedema therapists, support clinicians, GPs, for the 3 required levels of training.
27. Undergraduate education programmes should include a standardised lymphoedema module.
28. A GP online training programme for early detection and referral of lymphoedema should be developed and made available to all GPs.
29. 1 day Level 2 education programme for identified staff in community settings should be developed.
30. Research opportunities to be explored with universities in Ireland and abroad to improve lymphoedema and lipoedema care.

Implementation recommendations:

31. Establishment of a National Lymphoedema Implementation Group to lead the implementation plan over a two year period.
32. Establishment of standards of care for lymphoedema managed by an Expert Group.
33. Development/agreement of KPI's to ensure compliance across sites, service development and outcomes for services and quality improvement.
34. Recruitment of a National Clinical Lead, at Consultant grade, to lead, on a part-time basis, the development of the standards of care nationally, chair the Expert Group and to be responsible for the medical assessment of complex patients.
35. Recruitment of a Lymphoedema Clinical Project Manager to lead on the implementation plan.
36. Recruitment of the 9 Lead Lymphoedema Therapists.
37. Development of a comprehensive Communication Plan.

8. Conclusion

Lymphoedema and lipoedema are chronic diseases that are progressive and can have a severe impact on quality of life and socioeconomic issues. Lymphoedema can occur and be associated with many different medical areas e.g. oncology, dermatology and vascular services, which can lead to underdiagnosing and a lack of knowledge of treatment options for healthcare professionals. Lipoedema is often misdiagnosed as obesity and again treatment options not well understood for correct management, this is evident in the absence of an ICD 10 code for lipoedema. The prevalence of both conditions is predicted to increase in the future with increasing cancer diagnosis, ageing and obesity and it is essential that the current services are reformed to be able to offer a better service to current patients and to manage the demand in the future.

Cellulitis is a known complication of lymphoedema and chronic oedema is identified as the main reason for reoccurrence in half of all cellulitis patients. Medical treatment and hospital admissions related to lymphoedema and cellulitis are substantial and increasing every year. With appropriate treatment, as recommended in this Model of Care, cellulitis and its reoccurrence can be prevented with improved patient quality of life and significant cost savings for the HSE, including prevention of significant numbers of hospital admissions. Lymphoedema, if present, can also significantly hinder in the effective healing of leg ulcers. With correct management healing times can be drastically reduced with improved patient outcomes and savings in PHN visits, GP visits and dressings.

The current services are wholly inadequate and inequitable with no services available in some areas. Waiting times are excessive and there is a lack of standardisation and adequate service audit. There is a significant deficiency in awareness and education for lymphoedema/lipoedema in healthcare professionals. There is also a lack of consistency regarding prescribing and criteria for compression garments which are an essential part of lymphoedema/lipoedema management. There are adequate numbers of lymphoedema therapists but not enough dedicated hours for lymphoedema/lipoedema treatment. There are good areas of good practice and staff highly committed to providing best practice within their resources. In comparing the services to recognised international standards there are significant gaps which can be addressed by implementation of the MoC.

The MoC recommends an integrated treatment structure between acute and primary care services with specialist services available in primary care with an in-reach service to acute care. Prevention and early detection are a crucial aspect in the MoC. It is recommended that patients in all high risk areas are screened for risk and identified for intervention to reduce the risk and to detect the early onset of lymphoedema. Early detection and treatment will reduce the need for specialist treatment which is time consuming and costly and will improve quality of life for patients. The successful assessment and treatment of complex patients requires regional Specialist Lymphoedema Clinics with education and shared care an integral part of the services provided. As with all chronic diseases the model supports that the maintenance and self-management aspect of care, which does not require specialist services, are carried out close to the patient's home by appropriately trained staff. This MoC is in line with the HSE strategy of providing integrated care, reduced use of acute services through hospital avoidance and specialist services being available in the primary care setting. If delivered it will provide safe and efficient services with discernible value for money (for every €1M spent a year over €2.5m can be saved annually). It is estimated that over time the total annual cost savings could be approximately €13.9M once fully implemented.

This proposed model of care for lymphoedema is internationally recognised and, therefore, reflects an appropriate and sustainable approach to providing comprehensive lymphoedema services in Ireland. With reconfiguration, agreed standards of care and relatively moderate resource allocation, this model of care can be implemented and sustained to provide an excellent service for patients, reduce unnecessary costs for the health care service and provide more capacity for other patients to be treated.

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Appendix 1

Differentiating lipoedema from lymphoedema and obesity (Forner-Cordero et al, 2009; Langendoen et al, 2009; Fife et al, 2010; Child et al, 2010; Fetzer & Wise, 2015)

Characteristic	Lipoedema	Lymphoedema	Obesity
Gender	<ul style="list-style-type: none"> • Almost exclusively female 	<ul style="list-style-type: none"> • Male or female 	<ul style="list-style-type: none"> • Male or female
Age at onset	<ul style="list-style-type: none"> • Usually 10–30 years 	<ul style="list-style-type: none"> • Childhood (mainly primary); adult (primary or secondary) 	<ul style="list-style-type: none"> • Childhood onwards
Family history	<ul style="list-style-type: none"> • Common 	<ul style="list-style-type: none"> • Only for primary lymphoedema 	<ul style="list-style-type: none"> • Very common
Areas affected	<ul style="list-style-type: none"> • Bilateral • Usually symmetrical • Most frequently affects legs, hips and buttocks; may affect arms • Feet/hands spared 	<ul style="list-style-type: none"> • May be unilateral or bilateral depending on cause 	<ul style="list-style-type: none"> • All parts of the body • Usually symmetrical
Effect of dieting on condition	<ul style="list-style-type: none"> • Weight loss will be disproportionately less from lipoedema sites 	<ul style="list-style-type: none"> • Proportionate loss from trunk and affected limbs 	<ul style="list-style-type: none"> • Weight reduction with uniform loss of subcutaneous fat
Effect of limb elevation	<ul style="list-style-type: none"> • Absent or minimal 	<ul style="list-style-type: none"> • Initially effective in reducing swelling; may become less effective as the disease progresses 	<ul style="list-style-type: none"> • None
Pitting oedema (Box 5, page 8)	<ul style="list-style-type: none"> • Absent or minor in the early stages of the disease 	<ul style="list-style-type: none"> • Usually present but pitting may cease as the disease progresses and tissues fibrose 	<ul style="list-style-type: none"> • No
Bruises easily	<ul style="list-style-type: none"> • Yes 	<ul style="list-style-type: none"> • Not usually 	<ul style="list-style-type: none"> • No
Pain/discomfort in affected areas	<ul style="list-style-type: none"> • Often • Hypersensitivity to touch in affected areas 	<ul style="list-style-type: none"> • May be uncomfortable • No hypersensitivity to touch 	<ul style="list-style-type: none"> • No
Tenderness of affected areas	<ul style="list-style-type: none"> • Often 	<ul style="list-style-type: none"> • Unusual 	<ul style="list-style-type: none"> • No
Skin consistency	<ul style="list-style-type: none"> • Normal or softer/looser 	<ul style="list-style-type: none"> • Thickened and firmer 	<ul style="list-style-type: none"> • Normal
History of cellulitis	<ul style="list-style-type: none"> • Unusual (unless lipolymphoedema is present) 	<ul style="list-style-type: none"> • Often 	<ul style="list-style-type: none"> • Unusual
Stemmer's sign (Box 4, page 7)	<ul style="list-style-type: none"> • Usually negative (unless secondary lymphoedema is present) 	<ul style="list-style-type: none"> • Usually positive 	<ul style="list-style-type: none"> • Usually negative

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Appendix 2

Recommended lymphoedema therapist posts

From the BLS National Tariff Advisory Document:

Lymphoedema Assistant Practitioner (Band 4): works at all times under the direction and guidance of a state registered practitioner, who would be responsible for treatment decisions and planning care. Undertakes basic assessment (e.g. measurement of limbs) and basic treatment (e.g. skincare). Administers simple multi-layer lymphoedema bandaging in conjunction with lymphoedema practitioners.

Lymphoedema practitioner (Band 5): plans care for those with uncomplicated lymphoedema and those with stable lymphoedema in long-term management including skin care, exercise, simple lymphatic drainage (SLD) and compression garments. Also performs simple bandaging under guidance of a practitioner at level 6 or above. Undertakes assessment, monitoring, patient support and information provision.

Lymphoedema specialist practitioner (Band 6): Manages all types of lymphoedema with a degree of autonomy and responsibility for own caseload under supervision of advanced lymphoedema practitioner.

Lymphoedema Advanced Practitioner (Band 7): Experienced clinical professional empowered to make high-level clinical decisions and who has high standards of clinical skills (including assessment and diagnosis) and theoretical knowledge.

Lymphoedema Consultant Practitioner (Band 8): High level strategic role in developing and managing services, perhaps for a health board or authority. Clinical commitment would be condensed and focus on complex cases and offering support to other team members”.

Non-specialist (or generalist practitioners): These are healthcare professionals (HCP) who are likely to come into contact with patients who have a predisposition to lymphoedema and who have the opportunity to care for patients with known lymphatic damage. They should have an awareness of the signs and symptoms, can offer basic skin care advice as a preventative measure and know who to refer onto should any oedema be present. An example is community nurses caring for those who are immobile and therefore may present with dependent oedema.

Appendix 3

Stakeholder Workshop

Lymphoedema Workshop

13th December 2017

Background

The Model of Care (MOC) for lymphoedema treatment services in Ireland is nearly finalised and it was agreed by the Lymphoedema/Lipoedema Working Group Lymphoedema/Lipoedema Working Group Lymphoedema/Lipoedema Working Group to organise a workshop for all stakeholders in order to validate the MOC.

The aim of the workshop was to enable all stakeholders to voice their opinions and ideas on a Model of Care for lymphoedema and the information used to identify any gaps in the proposed Model of Care.

The stakeholders invited to the workshop were; representation from service users, MLD Ireland, National Lymphoedema Framework Ireland, Irish Cancer Society (ICS), HSE; primary care, acute, National Clinical Programmes (NCP) and palliative services. Representation from the ICS and the NCP were unable to attend.

Methodology

There were forty stakeholders able to participate N=40. Four facilitators were appointed and each group were asked to nominate a scribe. A coordinator oversaw time keeping and final roundup.

Each question was discussed for 10 minutes with 5 minutes then given for feedback within each group. Following completion of all questions the groups then fed back to the coordinator.

Three questions were agreed in order to establish the needs of the stakeholders for inclusion into the MOC;

Question 1 What components would you expect to see in a Model of Care for lymphoedema?

Question 2 What are the barriers and facilitators to implementation of a Model of Care?

Question 3 How do we overcome the barriers?

The results from the questions fell into four main themes summarised in **Figure1**

Figure 1: Summary of the main themes arising from the workshop.

Theme	Components	Gaps/ Inclusion in MOC
Early identification	Prevention as a priority Standardised baseline measurements. Equality for all patients. Diagnosis pathway. Self-care/management. Recognition Patient education-correct advice Prophylactic garments	Included in the MOC
Education	Best practice standards CPD structure Undergraduate education Research and conferences Self-care/management	Included in the MOC

	Recognition HSE e learning Mind set	
Pathway/treatment	Access for all patients Paediatric service Integrated acute and primary care Equality Health and wellbeing- obesity management Geography and mapping of services Patient centred At a regional level No division, public/private mix Community groups Population based	Included in the MOC. Obesity will be managed alongside the Health and Wellbeing strategy.
Governance	National centre of excellence National clinical lead Clinical consultant Minimum data set Resources allocation, ring-fenced Learning from other countries Clear and transparent Money savings; cellulitis Technology and standard outcomes	Included in MOC

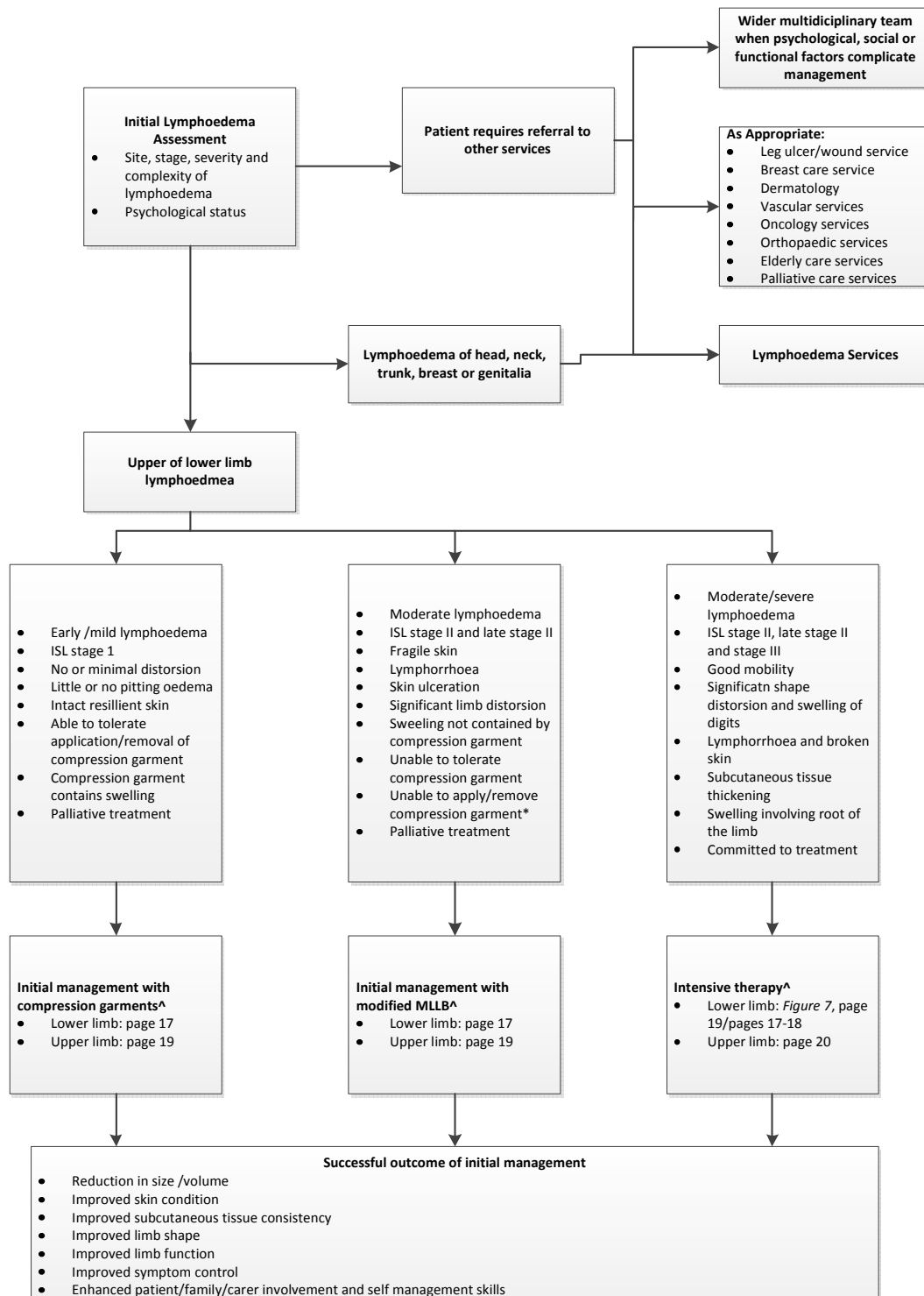
Conclusion

The MOC addresses all themes and underlying issues that were raised in the workshop and it can be concluded that the MOC reflects the opinions of the stakeholders.

Appendix 4

Treatment Algorithms for Lymphoedema and Lipoedema

Treatment for Lymphoedema

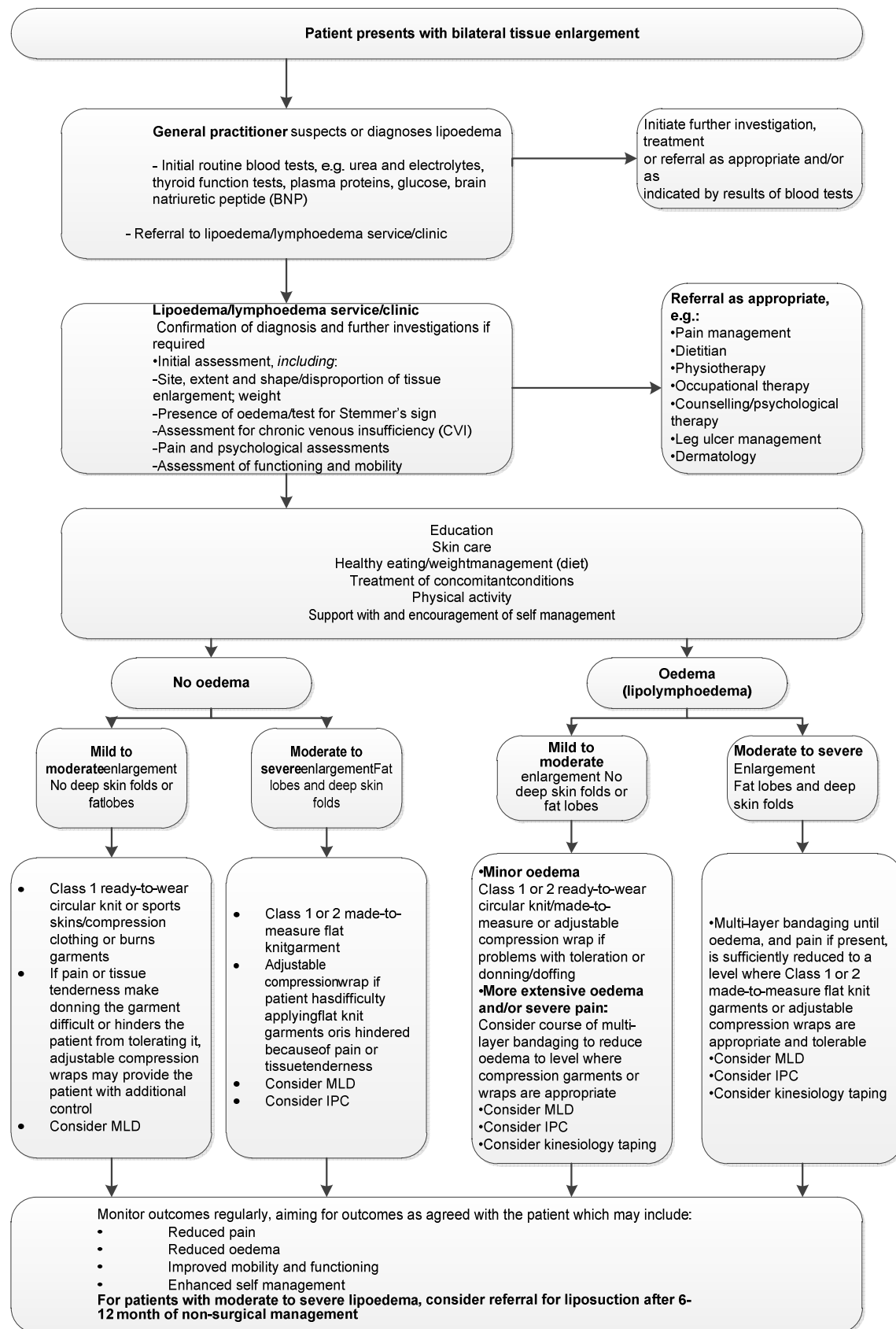


*If problems with garments are likely to be on going, careful consideration should be given to commencing MLLB because it may be required long-term.

^Includes skin care, exercise/movement and elevation. Please see text for practioner roles

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Treatment for Lipoedema



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Appendix 5: BREAKDOWN OF STAFFING COSTS							
	Therapy Staff (aligned to Senior Therapy grade)	Therapy Specialist (9 posts for SLC - aligned to Therapy Specialist grade)	Multi-task Attendant (aligned to therapy assistant)	Project Manager (Grade VIII)	Consultant		
Mid-Point of Salary Scales used for all staff (revised salary scale at 1/1/2018)	€56,133.00	€61,616.00	€31,418.00	€72,127.00	152,474.00		
EPRSI @ 10.75%	€6,034.30	€6,623.72	€3,377.44	€7,753.65	16,390.96		
Non-Pay @ 10%	€5,613.30	€6,161.60	€3,141.80	€7,212.70	15,247.40		
Salary Total	€67,780.60	€74,401.32	€37,937.24	€87,093.35	184,112.36		
BREAKDOWN OF COSTS PER CHO AREA							
CHO Area	No. of Therapy Staff Posts WTE	Cost of Therapy Posts	No. of Lead Lymphoedema Therapist Posts WTE	Cost of Lead Therapist	No. Multi Task Attendants Posts (WTE)	Cost of MT Attendant	Total Therapy & Multi-Task Attendant Staff Costs (Excluding Project Manager & Consultant)
CHO 1	1.9	€128,783.14	1.00	€74,401.32	1	€37,937.24	€241,121.69
CHO 2	3.2	€216,897.91	1.00	€74,401.32	1	€37,937.24	€329,236.47
CHO 3	2.3	€155,895.37	1.00	€74,401.32	1	€37,937.24	€268,233.93
CHO 4	6.1	€413,461.64	1.00	€74,401.32	1	€37,937.24	€525,800.20
CHO 5	4	€271,122.39	1.00	€74,401.32	1	€37,937.24	€383,460.95
CHO 6	3.4	€230,454.03	1.00	€74,401.32	1	€37,937.24	€342,792.59
CHO 7	5.4	€366,015.23	1.00	€74,401.32	1	€37,937.24	€478,353.78
CHO 8	5.4	€366,015.23	1.00	€74,401.32	1	€37,937.24	€478,353.78
CHO 9	4.4	€298,234.63	1.00	€74,401.32	1	€37,937.24	€410,573.18
Total	36.1	€2,446,879.57	9.00	€669,611.88	9	€341,435.16	€3,457,926.61
Implementation Team							
Project Manager (Grade VIII)		1		€87,093.00			
Consultant x 2 days per week (based on Type A contract type - revised salary scale 1/4/2018 - 4th point)		0.4		€73,000			
Total				€160,093			
OVERALL STAFF COSTS - PAY & NON-PAY							
STAFFING	Non Pay Costs		Pay Costs		TOTAL COSTS		
Therapists x 36.1	€202,640.13		€2,244,239.53		€2,446,879.66		
Lead Therapist x 9	€55,454.40		€614,157.48		€669,611.88		
Multi-Task Assistants x 9	€28,276.20		€313,158.96		€341,435.16		
Project Manager x 1	€7,212.70		€79,880.65		€87,093.35		
Consultant x .4	€6,099.00		€66,901.00		€73,000.00		
TOTAL STAFF COSTS	€299,682.43		€3,318,337.62		€3,618,020.05		



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