LYMPHOEDEMA SERVICES

REPORT OF THE LYMPHOEDEMA SERVICES REVIEW GROUP

SEPTEMBER 2004
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EXECUTIVE SUMMARY

Introduction

“As a sufferer of lymphoedema now for several years, I have had no help from any source”.

Lymphoedema is a tissue swelling due to a failure of lymph drainage. It is chronic and incurable. It may arise as a congenital absence or abnormality of lymph tissue or due to trauma such as cancer or its treatments. Lymphoedema is a progressive disorder, carrying high levels of psychological, physical and social distress. Patients who suffer from lymphoedema need equity of access to a uniformly high standard of service which can help them to contain their condition and to improve their quality of life.

This Report anticipates that in Northern Ireland the expected range of new cases of primary lymphoedema is around 20 per year with 105 – 585 new cases of lymphoedema secondary to cancer per year. There is no firm data on secondary non-cancer lymphoedema cases. In relation to the prevalence of lymphoedema, this Report concludes that there may be around 2257 people in Northern Ireland with lymphoedema.

However, these figures are estimates. More precise information on the current number of people with lymphoedema living in Northern Ireland and requiring treatment is not known as statistical data on lymphoedema patients is not routinely recorded. In addition, many patients remain undiagnosed.

The lack of evidence regarding the prevalence of lymphoedema seems to have influenced the development of services for people who suffer from lymphoedema in that it is difficult to argue the need for a service where there is limited evidence to support such a proposal. As lymphoedema often remains undiagnosed, any figures presently available are unlikely to be representative of the true number of cases.

Current provision of services

In general, there is limited provision of lymphoedema education and a lack of knowledge or awareness amongst healthcare professionals, leading to under diagnosis and inappropriate management of patients. For example, one of the lymphoedema patients, who has had primary lymphoedema for 33 years, said in response to the lymphoedema users survey, “Treatment has worked well but getting referred for the treatment has been hard work. I only received treatment in the last year”.
The survey of HPSS provision of lymphoedema care, which was commissioned by the Review Group, has revealed a distinct lack of lymphoedema care. There is inequality in service provision, with some areas having a limited service and other areas having no service at all. There is also inequality in access to service provision for patients with cancer related lymphoedema and patients with non-cancer related lymphoedema. One telling response to the survey from one of the HSS Trusts said:

“Basically patients are “managed” as best we can, having no service or trained staff”.3

There are very few practitioners who are qualified to provide a full range of lymphoedema treatments. Currently practitioners who are trained in lymphoedema assessment and management undertake this work in conjunction with their other job requirements. As a result, many lymphoedema healthcare professionals can have problems with professional isolation, cover for leave and waiting lists.

The lack of separate budgets for lymphoedema care also impacts on service provision as lymphoedema services are mainly funded from within allocations for cancer services or physiotherapy services. Moreover, there has been no evaluation or analysis of different models of lymphoedema service provision.

The Review Group was established to consider the nature and level of services currently available for people in Northern Ireland with primary and secondary lymphoedema and to make recommendations for the future provision of these services. Following detailed consideration of local, national and international issues related to lymphoedema, the Review Group has developed a series of recommendations for the development of a specialist lymphoedema network to facilitate the implementation of a high quality standard of lymphoedema care, which is realistic and achievable. These recommendations were developed with the help of users of lymphoedema services and the Review Group is grateful to all those who made such a valuable contribution from their first hand experience of lymphoedema.

This Report aims to inform commissioners and providers of services about the best way of developing lymphoedema services to ensure that people with lymphoedema in Northern Ireland receive cost effective, equitable and high quality lymphoedema services, based on the best evidence available. The Review Group hopes that the Department of Health, Social Services and Public Safety will accept the Group’s recommendations and that resources will be made available over the next few years to implement the proposals in this Report for the good of all people with lymphoedema in Northern Ireland.

The key recommendations of the Review Group are outlined in the following section.
KEY RECOMMENDATIONS

1. (A) **Lymphoedema Network:** A Northern Ireland network of lymphoedema services should be established. Patients with primary and non-cancer related lymphoedema should have equal access to the service. Commissioners and providers should develop an integrated network of lymphoedema services in each Board area to provide a high quality standard of care, which is realistic and achievable.

   (B) **Specialist Lymphoedema Clinics:** The Review Group recommends that commissioners and providers as part of the network should establish a specialist lymphoedema clinic at Belfast City, Altnagelvin, Antrim, Craigavon and the Ulster Hospitals. In addition to the specialist lymphoedema clinics, it is recommended that commissioners should work towards the provision of more local services, for example at local hospitals or treatment centres or hospices.

   (C) **Trained Lymphoedema Network:** The specialist lymphoedema clinics should be run by a trained network of lymphoedema practitioners. They should have good communication links and care pathways with other relevant hospital services, in particular the cancer centre and cancer units, and hospices but also with dermatology, vascular, tissue viability services and primary care.

   (D) **Practitioners:** The Northern Ireland lymphoedema network should have 6 WTE dedicated specialist lymphoedema practitioners, who would work to agreed guidelines and protocols in the specialist lymphoedema clinics. Northern Ireland should also have 9 WTE trained lymphoedema practitioners, who would work to agreed guidelines and protocols with the specialist lymphoedema practitioners.

   (E) **Assistants:** 6 WTE healthcare assistants should be appointed to the lymphoedema network to help free up lymphoedema practitioners’ time from more routine duties. 6 WTE clerical administrative staff should be appointed to assist in the operation of a Register of Lymphoedema Patients and other administrative support tasks.

   1. (F) **Consultant medical practitioner:** Commissioners and providers should ensure that a consultant medical practitioner, based at the specialist lymphoedema clinics, develops a specialist interest in lymphoedema patients.

2. **The management of Lymphoedema should include the following elements:**

   (A) **Prevention:** Prevention and early recognition are extremely important. All patients who have had surgery or radiotherapy or have other recognised risk
factors, which put them at risk of developing lymphoedema, should be informed of this risk and given written and verbal information on how to minimise their risk of developing lymphoedema.

(B) **Referrals:** When lymphoedema is suspected, the patient should be referred promptly to the multidisciplinary lymphoedema team for a holistic assessment by a trained network of lymphoedema practitioners. Commissioners and providers should ensure that adequate referral pathways are in place.

(C) **Assessment:** Patients should be assessed for lymphoedema in a way that involves a standardised diagnosis with patient centred criteria, including levels of pain, effect on quality of life and psychological impact. Relevant equipment should be made available to enable the correct measurement of limb volume and garments.

(D) **Treatment and Management:** All lymphoedema clinics should offer a comprehensive lymphoedema management service, with intensive daily Decongestive Lymphoedema Therapy (DLT)/ Complex Decongestive Therapy (CDT) being available as needed. Treatment and management should be appropriate for each individual patient’s needs, with appropriate review and surveillance arrangements in place.

(E) **Guidelines:** The Department’s Clinical Resource Efficiency Support Team (CREST) should be asked to undertake a rigorous assessment of the literature on treatment effectiveness for lymphoedema and to develop guidelines for prevention, assessment and treatment of lymphoedema with agreed patient focused outcome measures. Research activity should be an inherent part of the regional model of care.

3. **Education and Training:** Healthcare professionals generally should have more informed education and awareness about diagnosis, best practice and prevention. The lymphoedema practitioners within the network should be fully trained in one of the recognised schools of lymphoedema management. Providers of lymphoedema services should ensure that practitioners are competent and are following best practice. Health and Social Services Boards should undertake an education and training needs analysis to determine the training required to enable the implementation of lymphoedema services along the lines of the proposals in this report.

4. **Register of Lymphoedema Patients:** A Register of Lymphoedema Patients should be developed regionally, with appropriate IT facilities made available to promote minimum data sets, link with other databases and facilitate audit. The Department, Boards and Trusts should give further consideration as to how the
database should be developed, bearing in mind patient consent and patient confidentiality issues, the Data Protection Act and Health and Care Number. Co-operation with the British Lymphology Society and the recently formed UK Lymphoedema Framework is recommended to ensure shared standards across the UK in approaches to care and in documentation.

5. **Regional Audit:** The Project Manager should undertake a detailed patient centred Regional Audit of Lymphoedema Services to inform best practice and the future delivery of lymphoedema service models.

6. **Resources:** Resources should be made available to provide patient centred lymphoedema services in line with the recommendations in this report. Resources should also be invested to incorporate Sentinel Lymph Node (SLN) Biopsy into standard breast care management. Commissioners and Trusts should undertake an analysis of the revenue and capital costs associated with the provision of lymphoedema services in their area network.

7. **Project Manager:** A Project Manager should be appointed initially for 2 years to take forward the development of lymphoedema services in line with the proposals in this report.

8. **Implementation Group:** An implementation group should be established. The implementation group should ensure that a strategic approach for training is developed for Northern Ireland.

9. **Further Review:** There should be a review of lymphoedema services in 2009 to consider progress and determine the need for further development of lymphoedema care.
GLOSSARY

LYMPHOEDEMA

Lymphoedema is tissue swelling due to failure of the lymph drainage. It is chronic and incurable and may occur in any limb, trunk, genitalia or the head and neck. It may be disfiguring, painful and disabling. It may be primary or secondary.

Primary lymphoedema occurs due to either congenital abnormality or absence of lymphatic tissue.

Secondary lymphoedema occurs due to disruption of the lymphatics arising from cancer or its treatments i.e. surgery or radiotherapy. It may also arise due to trauma, infection, chronic venous disease and some inflammatory skin diseases.

AT RISK GROUPS

This describes those patients who have had a treatment which predisposes them to developing lymphoedema. This is most commonly recognised in breast cancer patients, especially those who have axillary node clearance and mastectomy. The risk is life long and patients and professionals need to be aware of risk reduction strategies.

PHYSICAL THERAPIES

These describe the conservative treatments which can reduce and maintain lymphoedema. The components are skin care, exercise, manual lymphatic drainage (MLD) and multi layer lymphoedema bandaging (MLLB). This combination of therapies is often referred to as Decongestive Lymphoedema Therapy (DLT) or Complex Decongestive Therapy (CDT). It is applied in two phases. In the first intensive phase, it is applied on a daily basis by a specially trained therapist for up to 6 weeks. This is closely followed by the second maintenance phase which will continue for the rest of the patient’s life. It includes skin care, exercise and containment with compression hosiery.

MANUAL LYMPHATIC DRAINAGE (MLD)

This is the specialist use of specific massage techniques which produce a mild mechanical stimuli aimed at increasing activity in lymphatic tissue. Fluid is, therefore, moved from a congested area towards normally functioning lymphatics.
MULTI LAYER LYMPHOEDEMA BANDAGING (MLLB)

This is provided by a functional bandaging of the swollen limb by short stretch bandages which cause a significant increase in lymph drainage when the limb is exercised. It is used daily in the intensive phase of treatment and is used to breakdown fibrosis in the limb and to reshape the limb. It may also be taught to patients to use at night as part of their maintenance self-management therapies.

COMPRESSION GARMENTS

These are used to prevent swelling increasing and may be either a sleeve, stocking or tights. They require specialist measurement and fitting and are provided from secondary care. Some patients with complex needs require custom made compression garments.

CELLULITIS

A common complication of lymphoedema is inflammation/infection of the skin (cellulitis) which, if untreated, may progress to systemic infection (septicaemia).

NORTHERN IRELAND LYMPHOEDEMA SUPPORT GROUP

The Northern Ireland Lymphoedema Support Group (NILSG) was established in 2002 and is registered as a charity by the Inland Revenue under reference XR68639.

The NILSG is a broadly based group, whose members include people from all over Northern Ireland who suffer from lymphoedema, their families and friends, and doctors, physiotherapists and nurses.

The aims and objectives of the NILSG are:

- To provide support for people with lymphoedema.
- To provide information about lymphoedema and its treatment
- To work towards the availability of better resources for lymphoedema treatment
- To maintain contact with health care professionals in lymphoedema management.

The NILSG can be contacted by email at nilsg@hotmail.com
CHAPTER 1
INTRODUCTION

“I have never had any help in the past 32 years except one pair of stockings”.

Introduction

1.1. This review was commissioned by the Chief Medical Officer in February 2003 to make recommendations to help commissioners and providers of lymphoedema services and the primary care sector meet the needs of those who suffer from lymphoedema. We are grateful to all of those patients with lymphoedema and to the committed professionals who care for them for taking the time to contribute to the lymphoedema review.

Context

1.2. The review took place in the context of local and national factors. The 1996 Campbell Report “Cancer Services – Investing for the Future” made significant recommendations for the organisation and delivery of cancer services, including the establishment of the cancer centre and cancer units and multiprofessional specialist cancer teams. The 2000 Palliative Care Report “Partnerships in Caring” set out proposals for the future direction of palliative care services. In February 2003 the then Minister, Des Browne, announced his decisions on the proposals in “Developing Better Services” for the future development of acute hospital services. The principles and guidelines in these documents have been taken into account when developing these proposals for lymphoedema services.

1.3. Specifically, the Department’s guidance for the management of gynaecological cancers, issued in February 2002, recognised the need for the development of lymphoedema services in Northern Ireland. The need to develop lymphoedema services was also recognised in the Western Health and Social Services Board area where a review was completed in December 2002. At national level, the National Council for Hospice and Specialist Palliative Care acknowledged that lymphoedema services needed to be further developed in the UK.

1.4. The review is timely in that other areas of the UK are also reviewing their lymphoedema services. A review of lymphoedema services has recently taken place in Wales. A National Service Framework for England is being developed for long term conditions which will cover some of the generic issues relevant to a wide range of people with long term conditions such as lymphoedema. It is expected that it will be published in 2004 for implementation in 2005.
1.5. Another initiative in England is the Lymphoedema Framework Project, a three year project funded by the King’s Fund to develop a national framework for lymphoedema management. The project, which commenced in February 2002 in Wandsworth (London), aims to provide sufficient evidence to persuade policymakers that lymphoedema is a major problem and is currently under resourced and for which national guidance on management is required.

Terms of reference

1.6. The aim of the Lymphoedema Services Review was to consider the nature and level of services currently available for people in Northern Ireland with primary and secondary lymphoedema and to make recommendations to improve the future provision of these services. Secondary lymphoedema was to include lymphoedema secondary to cancer and related therapy and other chronic conditions.

1.7. The terms of reference for the review were:

• to review the current provision of lymphoedema services in Northern Ireland for patients with primary and secondary lymphoedema;

• to establish the need for the further development of lymphoedema services, including referral and treatment arrangements;

• to make recommendations to the Department of Health, Social Services and Public Safety to ensure that patients within Northern Ireland receive cost effective, equitable high quality lymphoedema services based on the best evidence available; and

• to undertake the work in accordance with the principles and recommendations set out in the Campbell Report\(^4\) on the reorganisation of cancer services in Northern Ireland and in Developing Better Services.\(^6\)

Membership

1.8. Members of the Review Group were chosen for their potential contribution as individuals and not as representatives of particular interests. The membership of the Group is given at Appendix 1. Unfortunately one of the members, Mrs Wilma Compton, was unable to take up membership because of illness. Despite her illness, Wilma Compton wished to be kept informed of progress on the Review. The Review Group was saddened to learn of her untimely death and wishes to pay tribute to Wilma Compton’s commitment and dedication to advancing work to improve services for people with lymphoedema.
1.9. The Review Group was also deeply saddened to learn of the early death in August 2004 of another user representative, Mrs Olive McCann. Mrs McCann, the secretary of the Northern Ireland Lymphoedema Support Group, made a significant contribution in helping the Review Group to develop a greater understanding of the enormous physical, social, psychological and emotional impact which lymphoedema can have on individuals. Mrs McCann’s personal understanding of lymphoedema enabled her to play a very positive role in driving forward the work of the Review. Members appreciated her very helpful contribution, always made in a thoughtful and quiet manner.

Method of working

1.10. The Review Group considered that it was important to include the views and opinions of people with lymphoedema such as Wilma Compton and Olive McCann. Another patient, Mrs Breige O’Kane, Chairperson of the Northern Ireland Lymphoedema Support Group, participated as an active member of the Review Group. User views were further gathered when representatives from the Review Group met with the Northern Ireland Lymphoedema Support Group and the Derry Lymphoedema Support Group. A questionnaire was also issued to members of the support groups to find out the views of lymphoedema patients on the current provision of services. The findings are discussed in Chapter 4. In addition, the Group invited comments from the LILAC lymphoedema users’ group in Coalisland.

1.11. The Group also invited views about lymphoedema from the public, users and health professionals through the issue of a Departmental press release in March 2003. As a result, several lymphoedema patients contacted the Group to put forward their views.

1.12. This report hopes to reflect the views of people with lymphoedema and their experiences, together with those of professionals, into the recommendations for future service delivery. In this respect, people with lymphoedema were very ably represented by the expert patients who took part in the Review Group.

1.13. The Group also considered it important to consider the evidence of efficacy of treatment for lymphoedema. Literature reviews were undertaken and representatives from the group also visited the Foldi Clinic in Germany and a Lymphoedema Beacon Study Day held by the Southern Derbyshire Specialist Palliative Care Service. Some members of the Group also attended the International Congress of Lymphology Conference in Freiberg where they had opportunity to hear a range of presentations from lymphoedema experts and to discuss related issues.
1.14. In order to inform further the work of the Group, it was decided to establish the following sub-groups:

- epidemiology
- education and training
- definitions, treatment, effectiveness and standards of care
- views of people with lymphoedema
- HPSS provision
- voluntary sector
- primary and non cancer related lymphoedema
- resources
- equality
- implementation.

Equality, Targeting Social Need and Human Rights

1.15. The Review Group also took account of equality, targeting social need and human rights issues.

1.16. Section 75 of the Northern Ireland Act 1998 requires public authorities in carrying out their functions to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status, sexual orientation, gender, disability and persons with dependents or without.

1.17. The Department of Health, Social Services and Public Safety has identified the development of lymphoedema services as a new policy requiring Equality Impact Assessment (EQIA). Accordingly, the Lymphoedema Review Group, which was established to develop the strategy, carried out an EQIA. This is detailed in Chapter 11.

1.18. The new Targeting Social Need (New TSN) policy aims to tackle poverty and exclusion by targeting the efforts and available resources of public agencies towards the people, groups and areas objectively defined as being in greatest social need. New TSN includes a special focus on tackling the problems of unemployment, but also targets inequalities in health, housing, education and other policy areas. Specific areas of concern within the Department’s business area include:

- the inequalities which exist in health, many of which are associated with differences between affluent and deprived communities;

- the difficulties in accessing services faced by people in rural areas; and
that people in some of the Section 75 equality groups may not, for various reasons, use health and social services to the same extent as people from other population groups with similar levels of morbidity.

1.19. The Department aims to ensure that the implementation of the Lymphoedema strategy is compatible with New TSN requirements.

1.20. Another important consideration is the Human Rights Act 1998 which came into force in October 2000. It provides additional focus and emphasis to the rights and freedoms guaranteed under the European Convention of Human Rights. There are some 18 Convention rights and protocols which range from the Right to Life to the Right to Education. The Act requires legislation, wherever enacted, to be interpreted as far as possible in a way that is compatible with the Convention rights and makes it unlawful for a public authority to act incompatibly with the Convention rights. If it does act incompatibly, the Act allows a case to be brought to court or tribunal against the public authority. The Review Group is satisfied that the recommendations for the future provision of lymphoedema services are compatible with the Human Rights Act.
WHAT IS LYMPHOEDEMA AND HOW COMMON IS IT IN NORTHERN IRELAND?

“Lymphoedema is a life sentence not a death sentence”

What is lymphoedema?

2.1. The term ‘lymphoedema’ is used to describe tissue swelling associated with reduced lymphatic drainage. It is a chronic condition usually affecting one or more limbs and, in some cases, involving the trunk, head or genital area.

“Nothing has helped (so far!). My arm and leg just get larger!”

The lymphatic system and how lymphoedema develops

2.2. The lymphatic system, like the blood circulation system, involves the whole body. It is an extensive network of thin-walled vessels and around 700 lymph nodes. The lymphatic vessels collect fluid and various waste products from the skin and internal organs and return them to the blood circulation system. Reduced lymphatic drainage can result from damage to the lymphatic system, which can be due to cancer surgery, radiotherapy, infection or trauma, or from abnormalities in its formation, which can be a congenital or inherited condition. In turn, reduced lymphatic drainage, if it persists, leads to the development of lymphoedema.

2.3. Lymphoedema differs from other forms of chronic oedema in that the swelling is not due to fluid accumulation alone. In lymphoedema there is fibrosis that leads to the skin becoming hard and thickened. Over time these progressive changes can result in ‘elephantiasis’ - in which the limb becomes grossly swollen with coarsening and folding/wrinkling of the skin. This is illustrated in photographs at pages 46 and 47.

2.4. A common complication of lymphoedema is inflammation/infection of the skin (cellulitis) which, if untreated, may progress to systemic infection (septicaemia). “No doctor has ever discussed or suggested any treatment after initial diagnosis other than antibiotics for recurrent cellulitis”. “Only ever diagnosed with cellulitis not formally with lymphoedema”.

2.5. Lymphangiosarcoma, is a type of cancer which extremely rarely occurs as a late, but potentially fatal, complication of lymphoedema.
2.6. Although increase in size is the most obvious feature of lymphoedema, about one half of patients experience pain or discomfort. Lymphoedema has significant impact on individuals’ quality of life, with particular emphasis on their ability to function physically and socially. The ability to perform simple daily activities such as dressing may be impaired. Many patients also suffer from associated psychological and emotional problems.

“As a sufferer of lymphoedema now for several years I have had no help from any source. I have lymphoedema in my legs and they are constantly swollen. I can’t wear skirts and can’t get shoes to fit my feet. My life this past 7 years has been a constant struggle and I have no quality of life because of this”.

2.7. Lymphoedema is much commoner in women than in men: in one study 83% of patients were women. While it can occur at any age, there is a clear increase in rate with age with high rates in people aged 65 years and over. Other risk factors are obesity and lack of physical exercise. This may mean that the incidence may increase in a society where obesity is increasing and national exercise decreasing.

Classification

2.8. Lymphoedema can be classified according to the cause as primary or secondary.

Primary

2.9. Primary lymphoedema is due to either congenital abnormalities or absence of lymph tissue. It can present for the first time at different ages: at birth, between age 1 year and 35 years (often with the onset of puberty) and over 35 years.

Secondary lymphoedema

2.10. Secondary lymphoedema generally develops as a result of damage or obstruction of the lymphatic system. It can occur as a consequence of cancer or its treatment (either surgical or radiotherapy), trauma or infection. It may also arise as a secondary consequence of chronic venous disease, including previous deep venous thrombosis, post cellulitis, trauma and some inflammatory conditions such as arthritis. One respondent to the survey said: “Surgeon did not recognise or admit to the symptoms I suffered”.

2.11. Lymphoedema is a recognised complication of treatment for breast cancer. Patients may have mild transient swelling in the first few days post–surgery but lymphoedema may develop months or years after this. In around 77% of cases it occurs in the first 3 years after treatment.
2.12. It may also occur after treatment in women of gynaecological cancers such as vulval cancer and cancer of the cervix and in men for prostate cancer. There is evidence that the older, more extensive surgical procedures were more likely to cause lymphoedema than the current more conservative measures. Supplementary treatment with radiotherapy also increases the risk of developing lymphoedema.

“I have had lymphoedema in my right leg since having surgery for cervical cancer in 1997. The lymphoedema occurred 18 months later. My treatment at [hospital] has been wonderful and all queries answered openly and honestly, sometimes with great humour which is very beneficial. I have nothing but gratitude for the staff at [hospice].”

The size of the problem from the published literature

2.13. A recent study in South West London attempted to determine the magnitude of lymphoedema/chronic oedema in the community and the likely impact on the use of health resources. The study identified 823 patients with lymphoedema, giving an estimated rate (prevalence) of 1.33/1000. Only 63% of these patients were receiving treatment for their lymphoedema. The authors commented that their estimates were likely to considerably underestimate the problem. They concluded that lymphoedema was a common but under-reported condition with a prevalence similar to leg ulceration. In relation to leg ulceration, there is a 10 per 1000 lifetime risk of leg ulcers with between 1.5 to 3 per 1000 active leg ulcer cases.

Primary Lymphoedema

2.14. Daane et al (1998) estimated an incidence rate for primary lymphoedema of 1.2 per 100,000 population. With a population of nearly 1.7 million, this would give an estimated 20 new patients per year in Northern Ireland. These patients tend to be younger at presentation than the secondary cases and to have normal life expectancy so the prevalence of primary lymphoedema will be high.

Secondary lymphoedema

2.15. A review of the literature on incidence of secondary lymphoedema in patients with breast cancer compared seven studies published between 1986 and 1997 from USA and Europe. The review found an incidence ranging from 6% to 30% although the majority of studies give an incidence between 20% and 25%. There were variations in the definition of lymphoedema, source of patients, length of follow up and measurement techniques. The reports with the shorter follow up tended to have lower incidences of lymphoedema. Werngren-Elgstrom and
Lidman\textsuperscript{23}, in a study of 54 women found an incidence of lymphoedema measured by volume displacement of 22\% following hysterectomy for cancer of the cervix.

2.16. In the past lymphoedema affecting the lower extremities previously occurred in 80\% of cases within 5 years after groin dissection. A study published in 1983 reported the presence of only mild or moderate leg oedema in about 20\% of cases after groin dissection, in patients with a range of different cancers but mainly malignant melanoma.\textsuperscript{24}

2.17. Hardy and Taylor (1999)\textsuperscript{25} estimated that 24\% (218) of patients seen over a four-year period at a lymphoedema service had non-cancer related lymphoedema. This included patients with lymphoedema secondary to trauma and patients with dependant and cardiac disease related lymphoedema.

2.18. Worldwide the main cause of lymphoedema, with 90 million cases, is filariasis. In the UK the main causes are chronic venous disease, including previous deep venous thrombosis (DVT), post cellulitis, contact dermatitis, recurrent angioedema and facial surgery.

2.19. Facial lymphoedema may be primary or secondary to rosacea, some connective tissue diseases, orofacial granulomatosis, cellulitis, contact dermatitis, recurrent angioedema and facial surgery.

2.20. Lymphoedema may also be a distressing symptom in the palliative or terminal stage of any cancer illness. The incidence of this is not well researched and the usual treatments may need to be modified so that they are acceptable to debilitated patients.

**How much lymphoedema is there in Northern Ireland?**

2.21. Based on the prevalence of lymphoedema found in the South West London study of 1.33 per 1000 population,\textsuperscript{20} in Northern Ireland the current number of cases is estimated at 2257 (1.697 million population estimate 2002, NISRA).

2.22. From the estimated incidence of primary lymphoedema of 1.2 per 100,000 population, there are likely to be about 20 new patients with primary lymphoedema per year in Northern Ireland.

2.23. In Northern Ireland there are about 1000 new cases of breast cancer, 400 new cases of gynaecological cancers and 500 new cases of prostate cancer per year (ref:NI Cancer Registry website). Using these figures and the best estimated
incidence rates of 20-25% for lymphoedema following breast cancer, this would give a range of **200-250 expected new cases** of lymphoedema secondary to breast cancer per year in Northern Ireland. Using the same estimate for gynaecological cancers and 10% as a “best guess” for prostate cancer, the estimated number of new cases of lymphoedema related to these three cancers would range from **330 to 400 per year**. However, the total number of people living with lymphoedema in Northern Ireland will be related to the survival rates for these cancers. As five-year survival improves with new treatments, there are implications for the future requirement of lymphoedema services.

**Conclusion**

2.24. There are a growing number of people living with lymphoedema who will require ongoing treatment, surgical supplies and support.

2.25. The estimated incidence and prevalence is not reflected in the number of people receiving outpatient treatment. There appears to be a diagnosis and treatment deficit in Northern Ireland giving a substantial unmet need for this group of people.
DIAGNOSIS, PREVENTION, TREATMENT AND STANDARDS

“No doctor ever discussed or suggested any treatment”.

3.1. There is a lack of knowledge and awareness about lymphoedema on the part of the professionals and patients. This leads to delayed diagnosis and referral and to poor preventive care.

3.2. The diagnosis is mainly a clinical one based on the patient’s history and typical clinical features. However, lymphoedema services should have access to the full range of diagnostic services, including Doppler scan, CT scan, MRI and lymphscintigraphy which may be necessary to confirm diagnosis or to exclude venous thrombosis or progression of malignant disease.

Referral

“Treatment has worked well but getting referred for treatment was hard work. Only received treatment in the last year”. (Patient who has had lymphoedema for 33 years).

3.3. When lymphoedema is suspected, the patient should be referred promptly to the lymphoedema service for assessment and treatment. As patients may initially be diagnosed by various health professionals, the point of entry to the multidisciplinary team may vary. The Review Group has drawn up a Patient Pathway at Appendix 2 which commissioners and providers may wish to consider in the development of services for people with lymphoedema. The assessment of patients and their subsequent treatment should involve the measuring of outcomes which are important to the patient such as pain, quality of life and social functioning as well as measures of limb volume which is the usual outcome measure used in monitoring response to lymphoedema treatment. Every patient should be assessed by a medical practitioner with adequate training and experience to make the diagnosis, exclude infection, thrombosis and progression of malignant disease.

Prevention

3.4. The incidence of secondary lymphoedema in breast cancer decreases with breast conserving surgery. At present breast conserving surgery is combined with axillary node clearance. The use of sentinel lymph node biopsy (SNLB) helps to reduce the incidence of lymphoedema.
3.5. Standard treatment for breast cancer usually involves removing a breast tumour (by either lumpectomy or mastectomy) and most of the lymph nodes in the underarm closest to the cancerous breast. Removal of the lymph nodes causes side effects in some patients, such as shoulder pain, swelling in the arm and numbness. When breast cancer spreads to the lymph nodes, it can appear in some nodes (known as sentinel nodes) before others. SNLB is a new technique in which only the sentinel lymph nodes are removed and tested for cancerous cells.

3.6. A large multi-centre trial in the UK (the ALMANAC trial) recently presented the first results from the SNLB trials in June 2004 and the early data shows reduced morbidity and hospital stays. It is likely that this will become the evidence base for the surgical management of breast cancer.

3.7. About 60% of all operable breast cancer patients would be eligible for SNLB which can be delivered on a 1 day stay or even as a day case. The long term benefits will be cost effective with reduced inpatient hospital stays, decreased rates of axillary morbidity and potentially reduced lymphoedema rates. The Review Group concluded that resources will need to be invested to incorporate SLN biopsy into standard breast care management. The Review Group also noted that recent research in SLN biopsy in gynaecological cancers would suggest a role for it and the scope to decrease the incidence of lymphoedema in gynaecological cancers.

3.8. All patients who have had surgery or radiotherapy which puts them at risk of developing lymphoedema should be informed of this risk and that it may not develop for several years. They should be given information on how to decrease their risk of developing lymphoedema, and healthcare professionals should also be aware of those prophylactic measures. These patients should be monitored to encourage early detection and treatment of lymphoedema.29

**Treatment of lymphoedema**

3.9. The aim of lymphoedema treatments is to encourage lymph transport by physical therapies. The skin is kept soft and infection free as possible. Limb shape and functional ability are restored and maintained as much as possible. The patient is also supported in developing a self help programme to maintain treatment given and to come to terms with, and adapt to, a disabling life-long condition.
Physical therapies

3.10. This comprises skin care, exercise, manual lymphatic drainage (MLD) and multilayer lymphoedema bandaging (MLLB). This combination of therapies is referred to as Decongestive Lymphoedema Therapy (DLT) or Complex Decongestive Therapy (CDT). It is applied in two phases. Firstly, in the intensive phase, it is applied on a daily basis by specially trained therapists for up to 6 weeks. This is closely followed by the second maintenance phase which will continue for the rest of the patient’s life as a self help programme. It includes skin care, exercise and containment with a compression garment and with top up MLD or MLLB as required.

3.11. It is also important that acute episodes of inflammation are detected and treated with appropriate antibiotics in keeping with local antibiotic policies. The evidence of prophylactic antibiotics in recurrent episodes is still inconclusive but they are generally used in practice. A review of the management of cellulitis is currently being undertaken by the Department’s Clinical Resource Efficiency Support Team (CREST), the outcome of which will form the evidence base for future care of cellulitis in Northern Ireland. Healthcare professionals should assess patients who have evidence of cellulitis for underlying lymphoedema.

Other therapies

3.12. The benzopyrone group of drugs have been used in some centres to treat lymphoedema as has debulking surgery and microsurgery on the lymph vascular system. These treatments have a poorly developed evidence base. They are not currently used in Northern Ireland and rarely in Great Britain. They may need to be considered as more standard treatment options if further evidence of their effectiveness becomes available.

Conclusion

3.13. The relative effectiveness of lymphoedema treatments, or its individual component parts, has not been fully evaluated due to the lack of rigorous clinical studies in the literature. There is also variability in the timing and intensity of treatments recommended by practitioners. This can lead to variability in the type of treatments which patients can experience throughout Northern Ireland.

3.14. The Review Group recommended that the Department’s Clinical Resource Efficiency Support Team (CREST) should be asked to undertake a rigorous assessment of the literature on treatment effectiveness for lymphoedema and to develop guidelines for prevention, assessment and treatment of lymphoedema with agreed patient focused outcome measures.
Standards in Other Countries

3.15. During the course of its work, the Review Group considered the standards prevailing in other countries. In Europe lymphoedema therapists are licensed and certified by national boards of physiotherapy in each country.

3.16. In the USA there are currently no government-recognised national standards of treatment of lymphoedema or accreditation of lymphoedema training courses. In 2001, the Lymphology Association of North America (LANA), was founded to establish minimum competency standards for lymphoedema therapists and provide a national standardised certification examination (CLT-LANA).

Standards in the UK

3.17. In the UK the overall standard of care for people suffering from lymphoedema is poor and lacking in standardisation. There are currently no government-recognised national standards for treatment of lymphoedema or training of lymphoedema practitioners. The British Lymphology Society (BLS) is “a multi-disciplinary group of health care professionals and other interested parties directly involved in promoting the management of lymphoedema or interested in furthering the work of the Society.” The BLS, a voluntary organisation, has issued three documents:

‘Chronic Oedema Population and Needs 2001’ sets out in the ‘Definition of Need’ the minimum standard of care which people with lymphoedema, as per ‘Definition of the Population’ should expect.

‘Framework for Education’ sets out the training requirements for practitioners providing that care.

‘Strategy for Lymphoedema Care’ further defines the ‘minimum standards of care which should be offered by any lymphoedema service in the UK and Ireland.’

3.18. As a result of the lack of national standards for lymphoedema training, some practitioners may be expected to provide lymphoedema services with little in the way of training or mentoring. The Review Group recommends that those who treat patients with lymphoedema should be appropriately trained. Those who will provide prophylactic care and diagnosis to patients with lymphoedema, for example, cancer nurse specialists, should have a sound, certified knowledge of lymphoedema. They should know to whom referrals for more intensive treatments at specialist clinics should be made. Practitioners who treat lymphoedema should be fully trained in one of the schools of lymphoedema
management (Casley Smith, Vodder, Leduc, Foldi and Asdonc) and should have access to mentoring as they develop their clinical skills.

3.19. Those who are providing education should be satisfied about:

- The credentials of those responsible for the various schools, their expertise and medical experience in the treatment of lymphoedema
- The duration and content of the training provided, including anatomy, physiology and pathophysiology
- The training in comprehensive therapeutic measures, including skin care, MLD compression therapy and exercise, together with the medical indications and contraindications for MLD and CDT.
- Evidence of teachers’ and practitioners’ continuing professional development.

Training of other healthcare professionals in lymphoedema

3.20. In relation to healthcare professionals’ knowledge about prevention, it is concluded that all health care professionals should have knowledge regarding the potential development of lymphoedema. This is particularly important in the areas of:

- Cancer
- Vascular surgery
- Wound care/tissue viability
- Dermatology
- Primary care
- Palliative care
- Plastic surgery.

3.21. The Review Group also concluded that:

- Theory regarding lymphoedema development should be included in undergraduate programmes.
- Clinicians who treat patients deemed to be at risk should show evidence of knowledge of lymphoedema development in their continued professional development portfolios.
- Link clinicians should be available in all settings to ensure, facilitate and monitor awareness and promote onward referrals. They will be responsible for providing routine and formalised local prophylactic education/care on a ward, clinic or departmental basis.
VIEWS OF PEOPLE WITH LYMPHOEDEMA

“GPs in my practice do not take it [lymphoedema] seriously and I suffered for 2 weeks before I received proper treatment for cellulitis”.

Introduction

4.1. From the outset, it was considered important to include the views and opinions of people with lymphoedema in the Review. To this end, two patients, namely the Chairperson and Secretary of the Northern Ireland Lymphoedema Support Group, participated as active members of the Review Group. Users’ views were further gathered when representatives from the Review Group met with the Northern Ireland Lymphoedema Support Group and the Derry Lymphoedema Support Group. In addition, the Group invited comments from the LILAC Lymphoedema Users Group in Coalisland.

4.2. A short proforma was issued to members of the Northern Ireland Lymphoedema Support Group to find out the views of lymphoedema patients on the current provision of services. Consent to release of anonymised information for analysis in this report was sought from members who returned completed questionnaires.

4.3. Altogether 33 questionnaires were returned. As one respondent did not have lymphoedema, this form was excluded, leaving 32 for analysis. Of the 32, 7 had primary lymphoedema, 20 had secondary and in 5 the type was not known.

4.4. A detailed summary of the responses is available on request from NILSG to illustrate lymphoedema patients’ experiences about their diagnosis, condition and treatment. Some telling examples about the current provision of lymphoedema services have been included throughout this report. “GP told me there was no cure or treatment”.

4.5. On the more positive side, a few patients who have been able to access treatment have been happy with it. For example:

“Treatment has worked well but getting referred for treatment was hard work. Only received treatment in the last year”. (Note – this patient has had lymphoedema for 33 years).

“I have been more than happy with the treatment and therapy. The physiotherapist at [name of local hospital] is very attentive and is very good at applying her specialist skills”.

“I am now wearing a sleeve which is made to measure and more comfortable”.
Other views from people with lymphoedema

4.6. In addition to the questionnaire from the Northern Ireland Lymphoedema Support Group, the Review Group also invited views from the Derry Lymphoedema Support Group, LILAC Support Group and other people with lymphoedema. Some positive responses about treatment are as follows:

“I was referred to the hospice where [names of staff] were very helpful and explained everything to me about exercise and the care of my legs”.

“I have had lymphoedema in my right leg since having surgery for cancer in 1997. The lymphoedema occurred 18 months later. My treatment at [hospital] has been wonderful and all queries answered openly and honestly, sometimes with great humour which is very beneficial. I have nothing but gratitude for the staff at [hospice)”.

4.7. However, another response from a lady with lymphoedema demonstrates that the lack of lymphoedema services has impacted greatly on her quality of life.

“As a sufferer of lymphoedema now for several years I have had no help from any source. I have lymphoedema in my legs and they are constantly swollen. I can’t wear skirts and can’t get shoes to fit my feet. My life this past 7 years has been a constant struggle and I have no quality of life because of this”.

4.8. The impact on social activities is illustrated by another respondent who said:

“I would have walked miles every day. I can’t do that any more. I also loved line dancing and step dancing. I can go out on a slow one but I have to sit down before it is finished”.

Conclusion

4.9. The views of people with lymphoedema are very important in helping the HPSS to shape services appropriate for users. The main messages arising from the users’ survey are summarised as follows:

- There is a lack of knowledge about lymphoedema and its treatment amongst health care professionals
- Lack of appreciation of the impact of the condition on people with lymphoedema and their families
- Lack of information and advice for patients about the condition
- Patients have difficulty obtaining initial and ongoing care
- Patients have difficulty in obtaining suitable, well fitting compression garments.
4.10. The Review is grateful to all the people with lymphoedema who have taken part in the survey or who have otherwise informed the review about lymphoedema from a user’s perspective. This has been a crucial aspect of the Review and has significantly helped to inform the recommendations for the future delivery of lymphoedema services.
VOLUNTARY SECTOR PROVISION

“I was referred to the hospice where [names of staff] were very helpful and explained to me about exercise and the care of my legs”.

“I have nothing but gratitude for the staff at [name of hospice]”.

5.1. The above responses from patients illustrate that patients receiving treatment at hospices have been helped by the care provided. The provision of lymphoedema services in the voluntary sector is typical of how these services have developed in the UK with hospices spearheading their development. Lymphoedema is treated to some extent in all four hospices in Northern Ireland.

Foyle Hospice (Western Health and Social Services Board)

5.2. Originally Foyle Hospice started a lymphoedema clinic which offered services to all patients, including those with primary oedema. Two nurses provided lymphoedema services including assessment, MLD, fitting of compression garments and follow up. At the time of this report, only one nurse manages lymphoedema care. Although new patients are not being taken on, existing patients are followed up and looked after. Compression garments are ordered and paid for through the Oncology Department at Altnagelvin Hospital.

Foyle Hospice - Available statistics are as follows.

<table>
<thead>
<tr>
<th>YEAR</th>
<th>NEW PATIENTS</th>
<th>OUT PATIENT EPISODES</th>
<th>IN PATIENT EPISODES</th>
<th>MLD SESSIONS</th>
<th>UPPER LIMB SESSIONS</th>
<th>LOWER LIMB SESSIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>2</td>
<td>101</td>
<td>7</td>
<td>62</td>
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</tr>
<tr>
<td>2000</td>
<td>5</td>
<td>71</td>
<td>3</td>
<td>52</td>
<td>N/K</td>
<td>63</td>
</tr>
<tr>
<td>2001</td>
<td>5</td>
<td>43</td>
<td>3</td>
<td>27</td>
<td>13</td>
<td>28</td>
</tr>
</tbody>
</table>
Southern Area Hospice (Southern Health and Social Services Board)

5.3. The physiotherapist at the Southern Area Hospice does not currently provide a lymphoedema service as she is only appointed on a temporary basis. However, she does measure and fit compression garments and fitted garments for 10 patients in the first 4 months of 2003. Patients requiring lymphoedema management are seen by physiotherapists at Daisy Hill Hospital. Three patients were referred by GPs from 1 January to 30 April 2003. The Southern Area Hospice, along with Daisy Hill Hospital, is benefiting from the New Opportunities Funding project for lymphoedema services from January 2004 to December 2006.

Marie Curie Centre (Eastern Health and Social Services Board)

5.4. Lymphoedema services are provided by 2 part-time physiotherapists. In 2002 there were 12 new inpatients with lymphoedema and 40 inpatient reviews and 3 new outpatients and 4 outpatient reviews.

Northern Ireland Hospice (Service provider for Eastern and Northern Health and Social Services Boards)

5.5. The Northern Ireland Hospice has offered a lymphoedema service since 1991. At present, the lymphoedema service is provided by two part-time physiotherapists who have been trained in the Leduc School of Lymphoedema Management.
### NI HOSPICE CARE: LYMPHOEDEMA OUTPATIENTS

<table>
<thead>
<tr>
<th>YEAR</th>
<th>NEW PATIENTS</th>
<th>TREATMENTS</th>
<th>HOURS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>6</td>
<td>79</td>
<td>72</td>
</tr>
<tr>
<td>1996</td>
<td>25</td>
<td>139</td>
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<td>1997</td>
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</tr>
<tr>
<td>1999</td>
<td>6</td>
<td>29</td>
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</tr>
<tr>
<td>2000</td>
<td>14</td>
<td>74</td>
<td>52</td>
</tr>
<tr>
<td>2001</td>
<td>12</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>2002</td>
<td>13</td>
<td>76</td>
<td>54</td>
</tr>
</tbody>
</table>

### NI HOSPICE CARE: INPATIENTS WITH LYMPHOEDEMA

<table>
<thead>
<tr>
<th>YEAR</th>
<th>TREATMENTS</th>
<th>HOURS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>291</td>
<td>123</td>
</tr>
<tr>
<td>1996</td>
<td>320</td>
<td>127</td>
</tr>
<tr>
<td>1997</td>
<td>257</td>
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<td>1998</td>
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<tr>
<td>1999</td>
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<td>2000</td>
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<td>53</td>
</tr>
<tr>
<td>2001</td>
<td>78</td>
<td>34</td>
</tr>
<tr>
<td>2002</td>
<td>64</td>
<td>34</td>
</tr>
</tbody>
</table>
CHAPTER 6
HPSS PROVISION OF LYMPHOEDEMA SERVICES

"Basically patients are "managed" as best we can, having no service or trained staff".3

Introduction

6.1. This chapter describes the nature and extent of lymphoedema services provided in the HPSS based on information forwarded by Health and Social Services Boards and HSS Trusts in response to a questionnaire issued by the Lymphoedema Services Review Group in April 2003. A copy of the questionnaire can be viewed on the Department’s website at www.dhsspsni.gov.uk.

6.2. Lymphoedema services are not "stand-alone" services but are generally provided within physiotherapy or oncology budgets. As such, it has not been easy to build a completely accurate picture of the services currently available. Nevertheless, an analysis of the responses gives a flavour of the type of services provided for patients with lymphoedema.

Service provision

6.3. The response to the questionnaire from one of the Trusts, quoted at the beginning of this chapter, is a typical illustration of the very inadequate provision of lymphoedema services in Northern Ireland. The majority of respondents indicated that either no lymphoedema services, or only very limited lymphoedema services, are provided, with many respondents identifying the need for further development of lymphoedema care.
6.4. Responses from the Trusts about service provision are summarised at Table 1 below.

**TABLE 1 - LYMPHOEDEMA SERVICES PROVISION**

<table>
<thead>
<tr>
<th>Dedicated Clinics</th>
<th>Dedicated Sessions</th>
<th>Ad hoc Clinics</th>
<th>Ad hoc Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ulster Hospital</td>
<td>Specialist nurse and physiotherapist provide lymphoedema services on two half days monthly</td>
<td>Royal Victoria Hospital</td>
<td>One physiotherapist provides a very limited ad hoc service for primary and secondary lymphoedema patients</td>
</tr>
<tr>
<td></td>
<td>Specialist trained oncology physiotherapist provides 27 hours a week.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belfast City/ Belvoir Park Hospitals</td>
<td>Specialist trained oncology physiotherapists provide services each week day for patients attending for chemotherapy and/or radiotherapy</td>
<td>South and East Belfast Trust</td>
<td>Physiotherapists provide community and outpatient services for patients with primary and secondary lymphoedema at Holywood Arches and Wellington Park Health Centres</td>
</tr>
<tr>
<td>North and West Belfast Trust</td>
<td>Pilot project – 14 hours weekly</td>
<td>Craigavon Area Hospital</td>
<td>Physiotherapists provide ad hoc services. MLD/MLLB/sleeves provided.</td>
</tr>
<tr>
<td>Daisy Hill Hospital</td>
<td>NOF pilot with Southern Area Hospice – physiotherapist and nurse provide 18 hours weekly</td>
<td>Craigavon and Banbridge</td>
<td>Community Macmillan Nurse Specialist offers advice to primary and secondary lymphoedema patients</td>
</tr>
</tbody>
</table>
6.5. The components of lymphoedema services include assessment/diagnosis; education/prevention; skin care; exercise; multi-layer compression bandaging; manual lymphatic drainage and the fitting of compression garments. However, Northern Ireland does not have a dedicated lymphoedema clinic which can offer complex treatments to patients who need them on a daily basis.

<table>
<thead>
<tr>
<th>Dedicated Clinics</th>
<th>Dedicated Sessions</th>
<th>Ad hoc Clinics</th>
<th>Ad hoc Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antrim Hospital</td>
<td></td>
<td></td>
<td>Ad hoc services provided by physiotherapist and breast care nurse</td>
</tr>
<tr>
<td>Braid Valley and Carrickfergus Hospitals</td>
<td></td>
<td>Trained general physiotherapists see primary and secondary lymphoedema patients.</td>
<td></td>
</tr>
<tr>
<td>Altnagelvin</td>
<td>Specialist trained oncology physiotherapist and specialist nurse provide lymphoedema services two half days monthly. Other patients are treated as needed.</td>
<td>Erne and Tyrone County</td>
<td>Ad hoc services provided by physiotherapists and nursing staff.</td>
</tr>
</tbody>
</table>
6.6. Patients presenting in the community with lymphoedema, whether primary or secondary, can be referred to a variety of services as outlined below.

- Community leg ulcer clinics
- Hospital dermatology clinics
- Hospital leg ulcer clinics
- Hospital vascular clinics
- Hospital general medical clinics
- Hospital general surgical clinics
- Hospital or community physiotherapy clinics
- Hospital oncology clinics.

6.7. The pattern of referral would appear to be haphazard, and is determined as much by local/regional availability as by clinical rationale. Because leg ulcer services have now extensive experience in lower limb compression bandaging, this route has become quite popular for management of ulceration and control of oedema. Lymphoedema patients with leg ulcerations should be treated in collaboration with leg ulcer clinics or tissue viability nurses. In addition, leg ulcer services, vascular clinics and dermatology clinics have access to compression hosiery, which further encourages this pattern of referral.

Patients treated

6.8. Trusts provided data about the numbers of patients treated for lymphoedema. It should be noted that the data is based on the best information available to Trusts as there are no specific hospital returns to capture this data at present.

6.9. The number of new outpatients treated increased from 182 in 1999/2000 to 321 in 2001/2002. Outpatient reviews grew from 617 to 1471 over the same period. 80 inpatients were treated in 1999/2000 with 78 treated in 2001/2002. In 2002/2003 60 inpatient episodes were recorded but this is likely to be an underestimation.

Waiting times

6.10. Information on waiting times for new lymphoedema patients, based on responses from Trusts, records that patients wait from up to 2 weeks to 10 months.

6.11. The Southern Health and Social Services Board also reported that 59 patients were awaiting treatment at the end of April 2003. In the Northern Board a multi-professional screening questionnaire piloted at Antrim Hospital records that, of the 71 patients identified with lymphoedema at oncology clinics, only 9 are known to physiotherapists. This would appear to demonstrate that there is unmet need for lymphoedema patients.
Training

6.12. Nurse training in lymphoedema care ranges from introductory courses, for example on lymphoedema and breast care, to university certificate level.

6.13. Responses from Trusts indicated that 14 physiotherapists have trained in lymphoedema management. Physiotherapy training in lymphoedema includes MLD, compression bandaging and the fitting of compression garments. Some physiotherapists are members of MLD UK. Responses from Trusts indicated that, in some cases, physiotherapists trained in lymphoedema management were unable to practise lymphoedema care because of other existing work commitments. It is also notable that the majority of Trusts recorded only one physiotherapist with any lymphoedema training which demonstrates that where lymphoedema services are provided, the physiotherapist is working single-handedly, with no cover arrangements.

6.14. Oncology physiotherapists at Belfast City Hospital Trust have been actively involved in raising awareness of lymphoedema across Northern Ireland. Over the last 5 years, training programmes have been run by nationally recognised specialist practitioners. At April 2003, 9 staff within Northern Ireland had completed specific lymphoedema training and 31 had general key worker skills. Belfast City Hospital Trust staff also provide undergraduate and post-graduate teaching to increase awareness of the condition and the need for early diagnosis and good prophylactic patient education.

Patient surveys

6.15. Following a survey of users of lymphoedema services in 1999 at Belfast City Hospital, a new information booklet was designed and piloted with the help of patients. No other surveys of lymphoedema patients or carers have been reported by Trusts within the last three years.

Information Services

6.16. The Physiotherapy Oncology Forum, which meets quarterly, has developed protocols, including one for lymphoedema, to aid service provision. Work is currently ongoing to review and standardise patient information leaflets and assessment sheets.

6.17. In the meantime, Trusts delivering lymphoedema services are providing patients and carers with a range of information including leaflets, details of support groups and videotapes.
Funding

6.18. Lymphoedema services are generally funded from physiotherapy or oncology budgets. In view of the lack of separate budgets for lymphoedema services, Trusts were unable to provide data about funding.

6.19. However, most Trusts emphasised the need for additional resources to provide adequate lymphoedema services. Some unsuccessful bids for funding for additional lymphoedema posts have been made, including service development bids for a lymphoedema specialist at Belfast City Hospital Trust.

6.20. Funding has also been received from the New Opportunities Fund following an audit in 2002 of the pilot lymphoedema service at Daisy Hill Hospital. £110,000 has been allocated from January 2004 to December 2006 to support the recruitment of 0.5 WTE physiotherapist and 0.25 WTE nurse to work 18 hours per week with 100 cancer-related lymphoedema patients and their carers at Daisy Hill Hospital and the Southern Area Hospice, with domiciliary visits accommodated where possible. The aim is to manage lymphoedema patients to increase the quality of life and provide more tailored and user-friendly garments within cost constraints.

Services Commissioned

6.21. Although Health and Social Services Boards do not specifically commission any lymphoedema services, some services are provided within overall Service Delivery Agreements for physiotherapy and palliative care. This is confirmed by the responses from Trusts. In a few cases, Boards have referred patients to Great Britain or Germany for treatment. Some patients have also been referred to a Foldi trained therapist in Donegal.

Future plans for development

6.22. Most Trusts have recognised that lymphoedema services need to be further developed and would be keen to expand and improve services subject to the availability of additional funding. For example, the Royal Group of Hospitals Trust has suggested that a structured lymphoedema service is required for cancer, vascular and other patients whilst the Ulster Community and Hospitals Trust has proposed that more key personnel will require further training in lymphoedema management and treatment.
6.23. The Western Health and Social Services Board has secured funding from the New Opportunities Fund to develop a lymphoedema network within Altnagelvin and Sperrin Lakeland areas, with emphasis on training practitioners and raising the awareness of lymphoedema and its prevention and treatment in other healthcare professionals. Altnagelvin has identified the following issues for urgent address:

- Referral process
- Practitioners available
- Level of practitioner training
- Where and by whom the service is provided
- The need for a dedicated lymphoedema service
- Cost of providing the service
- Knowledge about the service
- Communication to a wider audience.

Conclusion

6.24. It is recognised that the limited lymphoedema services which exist are provided by dedicated and committed health professionals, with evidence of user satisfaction for treatment received from specialists in lymphoedema care. Nevertheless, this chapter has concluded that there is evidence of unmet patient need and that the current provision of services for lymphoedema patients is inadequate. This Report has, therefore, developed recommendations for the future provision of lymphoedema services to enhance the limited level of services already provided by dedicated health professionals. Recommendations to improve the delivery of services for lymphoedema patients are discussed in more detail in the following chapters.
CHAPTER 7
"As a sufferer of lymphoedema now for several years, I have had no help from any source".

"GP told me there was no treatment".

"The reason I went to Dublin for treatment was because we had no one qualified in Northern Ireland to do this".

"My treatment at [name of hospital] has been wonderful".

Introduction

7.1. The views of people with lymphoedema, together with responses from the HPSS, have helped the Review Group significantly to gather information about the provision of lymphoedema services. In addition, the Review Group agreed that it was important to consider the results of local audits of lymphoedema services in order to inform their work. In particular, the Group considered:

(i) Regional audit of training in lymphoedema care;
(ii) Audit of gynaecological outcomes post cancer treatment; and
(iii) Audit of lymphoedema services at Altnagelvin Hospital.

7.2. The Review Group concluded that the findings of these audits were extremely useful in illustrating the level of lymphoedema management available across Northern Ireland. Further details on the audits are available on request from the DHSSPS on 028 90 520383.

7.3. The Review Group considered it particularly relevant to include a summary of the regional audit at Belfast City Hospital, which was undertaken in 2001/2002. The remit of this audit was to:

- evaluate the knowledge base of providers of prophylactic care;
- establish the present level of resources utilised for lymphoedema services;
- establish the actual skill level of practitioners; and
- establish the availability of services for non-cancer related lymphoedema.
7.4. The conclusions of this audit are summarised as follows:

- Clinicians in Northern Ireland reflect a poor understanding of lymphoedema and a lack of awareness of potential “at risk” patient groups.
- Prophylactic care/education is not available routinely for all “at risk” patient groups.
- Lymphoedema management/lymphology is not routinely taught at undergraduate level.
- 42% of practising lymphoedema clinicians have not attended a recognised course.
- All resources are extremely limited, with no specific specialist clinics, or dedicated clinicians.
- Counties Fermanagh and Tyrone recorded no trained clinicians.
- General resources are poor with limited access to multiprofessional support, accommodation and treatment provisions.
- Pressurised budgets and limited management support.
- As lymphoedema is a chronic condition, prevalence outnumbers incidence which necessitates constant review of service planning.

**Review Group’s conclusions**

7.5. The audit findings confirm the results of the questionnaires issued to the HPSS and the views of users in that there is a real need to establish equality of access to a uniformly high standard of care for all people with lymphoedema in Northern Ireland. In particular, the audit findings support some of the key recommendations of the Review Group. For example, audits concluded, amongst other things, that there was a lack of awareness amongst health professionals about lymphoedema and that there was a need for training, prophylactic education/care for all “at risk” patients, the establishment of specialist lymphoedema clinics and dedicated lymphoedema practitioners.

7.6. The Review Group considered that the findings of these three local audits are important in helping to identify the potential shape of a properly resourced lymphoedema service for Northern Ireland.
However, the Review Group concluded that there should be a detailed Regional Audit of Lymphoedema Services to inform best practice and the future delivery of lymphoedema service models. This should include patients’ views and experiences of services.

7.7. The Review Group also recommended that there should be a review of lymphoedema services in 2009 to consider progress and determine the need for further development of lymphoedema care.
CHAPTER 8
Diagnosis

8.1. Proper diagnosis of lymphoedema patients is of fundamental importance in any model of service. Patients need to be more aware of early symptoms, more informed about the need for early diagnosis and treatment and how to access the system. Specialist breast cancer nurses already have a particular role in educating patients about lymphoedema. District nurses and other cancer site-specific nurses also have the potential to educate and identify patients at risk of developing lymphoedema.

Treatment

8.2. The value of the practitioners currently involved in lymphoedema care is recognised. For example, one of the people with lymphoedema said in response to the user survey, “I have been more than happy with all the treatment and therapy”, while another said: “The physiotherapist at [local hospital] is currently treating me. She is very attentive and is very good at applying her specialist skills”.

8.3. Treatment and management of lymphoedema should encompass the 4 essential elements of DLT/CDT namely skin care, exercise, MLD and containment (garments and bandaging). All these 4 elements of DLT/CDT should be offered to patients, according to need, as a required standard. The Review Group recognised that many patients require full DLT/CDT, including MLD and MLB, when first presenting and that there is a need to move away from the perception that skin care, exercise and containment garment must always be tried first regardless of the stage and severity of their condition. In addition, relevant equipment should be made available to enable the correct measurement of limb volume and garments.

8.4. Case mix, whether judged on primary diagnosis or severity of the lymphoedema, will impact on the demands of staff time and on the types of containment/compression garments, dressings and bandages required. Currently some lymphoedema patients may also be admitted to hospital with septicaemia or cellulitis. Commissioners and providers should ensure that an appropriate level of care is provided for lymphoedema patients with cellulitis or septicaemia.
Lymphoedema network

8.5. The Review Group recommended that each Health and Social Services Board should develop an integrated network of lymphoedema services to provide a high quality standard of care, which is realistic and achievable. Such a network would encompass the specialist clinics, local hospitals, treatment centres and hospices. The Group has suggested a model for a lymphoedema network at Appendix 3.

Specialist lymphoedema clinics

8.6. It is recommended that commissioners and providers should establish a specialist lymphoedema clinic at Belfast City, Altnagelvin, Antrim, Craigavon and the Ulster Hospitals. This recommendation is in line with the Department’s 2002 guidance on the Management of Gynaecological Cancers which proposed the establishment of multi-professional lymphoedema clinics at these locations. Providing lymphoedema care in specialist units will ensure that patients are managed by appropriately trained health professionals. By seeing a high volume of patients, the specialist lymphoedema practitioners will be able to maintain their expertise.

8.7. The Review Group concluded that the specialist clinics should operate daily on week days. In addition to the specialist lymphoedema practitioners, the clinics should operate with an appropriate skills mix. For example, healthcare assistants could roll bandages and help patients dress and undress whilst administrative staff could assist in data collection and communication within the network and with relevant healthcare professionals.

Locality networks

8.8. In addition to the specialist lymphoedema clinics, it is recommended that commissioners should work towards the provision of more local lymphoedema services. Commissioners should also take into consideration the role of local hospices in providing lymphoedema care. In accordance with the principles of clinical networks set out in “Developing Better Services”, a network of lymphoedema care should operate between the specialist clinics, locality clinics, primary and hospice care to provide a continuum of lymphoedema services.

8.9. Lymphoedema services should also network with relevant cancer, vascular and dermatology teams. Such networks of lymphoedema services should be underpinned by treatment protocols and audit so that more convenient and accessible services can be provided for patients without compromising standards of care or treatment.
Referrals

8.10. There should be good communication links and care pathways between the specialist units, locality hospitals, hospices and primary care. Commissioners and providers should ensure that adequate referral pathways are in place. An example of a suggested patient pathway is included at Appendix 2.

Lymphoedema network practitioners

8.11. It is recommended that the lymphoedema clinics should be run by a trained network of lymphoedema practitioners. It is recognised that physiotherapists, cancer site-specific nurses and specialist palliative care professionals will have a particular role in the specialist lymphoedema clinics. Lymphoedema trained cancer site-specific nurses, in particular, will have an important part to play in educating patients about the risks of developing lymphoedema. A holistic approach to lymphoedema patient care, including social and psychological care, is also essential, with appropriate care management systems and networks being established.

Specialist lymphoedema practitioners

8.12. It is recommended that the Northern Ireland lymphoedema network should have 6 WTE dedicated specialist lymphoedema practitioners, who would work to agreed guidelines and protocols in the specialist lymphoedema clinics. The specialist practitioners would assume responsibility for quality, audit and education programmes, as well as the assessment, treatment and management of patients. A suggested job description is outlined at Appendix 4.

Lymphoedema practitioners

8.13. It is also recommended that Northern Ireland should have 9 WTE lymphoedema practitioners, who would work to agreed guidelines and protocols with the specialist lymphoedema practitioners. Appropriately qualified health professionals, trained in the management of lymphoedema, would be very suitable to carry out lymphoedema practitioner work. A proposed job description for a lymphoedema practitioner is at Appendix 5.

Lymphoedema assistants

8.14. The Review Group concluded that there should be 6 WTE healthcare assistants appointed to the lymphoedema network to help free up lymphoedema practitioners’ time from more routine duties, including rolling bandages,
cleaning couches and helping patients dress and undress. The Group also concluded that 6 WTE clerical administrative staff should be appointed to assist in the operation of a Register of lymphoedema patients and other administrative support tasks.

**Lymphoedema specialist medical practitioner**

8.15. Commissioners should also ensure that a consultant medical practitioner, based at the specialist clinics, develops a specialist interest in lymphoedema patients, for example, a specialist in palliative care medicine, or in some cases, a vascular surgeon or dermatologist with a specialist interest and training in lymphoedema.

**Project Manager**

8.16. The Review Group recommends that a Project Manager should be appointed initially for two years to take forward the development of lymphoedema services in line with the proposals in this report and to facilitate a regional audit of lymphoedema. An implementation Group should also be established.

**Education and Training**

8.17. Responses to the HPSS survey and to the users’ proforma indicate that healthcare professionals generally need more informed education and awareness about diagnosis, best practice and processes, as well as prophylactic education. Most practitioners would welcome the opportunity to undertake Continual Professional Development in lymphoedema. All healthcare professionals will in future be required to demonstrate their continued professional competence on a regular basis.

8.18. The establishment of specialist network of lymphoedema practitioners will have considerable implications for training. Training traditionally has taken place by learning on the job. There have been significant changes to this approach as it is recognised that it is not the most efficient way of equipping staff for specialist practice. Individual healthcare professionals must ensure that their professional development keeps their knowledge and skills up to date. This approach is emphasised in “Developing Better Services”6. Lymphoedema practitioners and specialist lymphoedema practitioners must be fully trained in a recognised school of lymphoedema treatment.

8.19. Education programmes will also be required for other health professionals, including primary care teams and cancer services teams. Appropriately trained
district and practice nurses and GPs will have an important role in primary care whilst staff in cancer teams, including cancer specialist nurses and palliative care nurses, could help to meet the need in secondary care. A high quality model of lymphoedema care must be supported by an informed primary, secondary and tertiary care.

8.20. The Review Group recommends that each Health and Social Services Board should undertake a training and education needs analysis to determine the training required to enable the implementation of appropriate lymphoedema services along the lines of the proposals in this Report. Various training courses are provided in mainland Europe and in Great Britain but recent developments by the University of Ulster and Macmillan should make lymphoedema training more accessible regionally. The Implementation Group should ensure the development of a strategic approach to training in Northern Ireland to make sure that those responsible for teaching lymphoedema treatments have the competencies to ensure the adequate training of practitioners.

8.21. The Review Group also recommends the inclusion of the anatomy, physiology and pathophysiology of the lymphatic system in the undergraduate curriculum of relevant healthcare professionals.

Protocols and guidelines

8.22. The Lymphoedema Review Group has recommended that the Clinical Resource Efficiency Support Team (CREST) should be asked to develop protocols and guidelines for lymphoedema care, including the development of guidelines for children with lymphoedema. These protocols and guidelines will greatly inform the implementation of best practice across the specialist networks and in the wider HPSS. However, commissioners and providers will be asked to commence work on the development of lymphoedema services pending the publication of the CREST guidelines to ensure that patients get the best possible care.

Information and advice

8.23. The specialist lymphoedema networks should act as a catalyst for the provision of advice, information and support to lymphoedema patients, carers and their families. The networks should assess and address individual patient need on a holistic basis with the aim of increasing patient confidence, motivation, competence and control, and to reduce disability and discomfort caused by the condition. Patients should have knowledge of local and national lymphoedema support groups and be involved in service developments and audit.
8.24. The multi-professional service should also provide a source of information and advice to healthcare professionals to facilitate the identification of patients at risk of developing lymphoedema, and the rapid assessment and treatment of those patients who do go on to develop lymphoedema. The model of service should aim to improve the quality of life and allow the patient to reach an optimum level of independence.

Communication

8.25. It was agreed by the Review Group that a regional communication network should exist between all lymphoedema practitioners/clinics and should operate in voluntary, acute and community service provision, to facilitate a network of lymphoedema services. This will facilitate a network of lymphoedema services, which will underpin a convenient and accessible service for patients without compromising standards of care or treatment through peer support, individual development, service development, information sharing, audit and research.

Lymphoedema Register

8.26. In order to inform future service provision, it is proposed that a database should be developed to register all lymphoedema patients. A register of patients would provide a good information base for monitoring the number of patients treated and the outcomes of treatment. The Review Group recommended that a Register of Lymphoedema Patients should be developed regionally, with appropriate IT facilities made available to promote minimum data sets, link with other databases and facilitate audit. The Department, Boards and Trusts should give further consideration as to how the database should be developed, bearing in mind patient consent and patient confidentiality issues, the Data Protection Act and the Health and Care Number. Co-operation with the British Lymphology Society and the recently formed UK Lymphoedema Framework is recommended to ensure shared standards across the UK in approaches to care and in documentation.

8.27. The Review Group also recommended that there should be a detailed Regional Audit of Lymphoedema Services to inform best practice and the future delivery of lymphoedema service models.

Equality of access

8.28. Although the majority of lymphoedema patients requiring treatment will have cancer related lymphoedema, commissioners and providers should also ensure that patients with primary and non-cancer related lymphoedema have equal access to the specialist lymphoedema practitioners. Services should be provided on the basis of clinical need, regardless of the underlying cause.
Conclusion

8.29. Responses to questionnaires from the HPSS and from people with lymphoedema have revealed a lack of lymphoedema services. “GP told me there was no treatment”, responded one patient with primary lymphoedema. “I was only ever diagnosed with cellulitis not formally with lymphoedema”, responded another patient. A third lymphoedema patient said “No I have never had any help in 32 years, apart from one pair of stockings”. The Review Group has concluded that there is a definite need to improve the current delivery of lymphoedema services, which are provided on a limited or non-existent basis.

8.30. The Review Group has recommended that each Health and Social Services Board should develop an integrated network of lymphoedema services to provide a high quality standard of care, which is realistic and achievable. It is recognised that improvements to the provision of lymphoedema services will not happen overnight but should increase over time as more staff are trained in the treatment and management of patients. The end result should enable lymphoedema patients to be treated early to ensure the best outcomes.

8.31. For now, an integrated service model based on current best evidence should be agreed and implemented. Commissioners will also want to maintain the future development of lymphoedema services on the basis of audit findings as recommended in the Department’s 2002 guidelines on the Management of Gynaecological Cancer. The development of protocols and guidelines by CREST should also enhance future models of service provision.

8.32. However, it is recognised that the pace of change in improving the provision of lymphoedema services will also depend on the availability of additional financial resources. Resource issues are discussed more fully in the following Chapter.
RESOURCES

Potential cost savings

9.1. Lack of treatment for lymphoedema can lead to increased swelling and pain, irreversible damage to the lymphatic system, recurrent infections, the inability to work and reduced psychological well being and quality of life. Potential cost savings could be realised from more effective management of lymphoedema patients, particularly in relation to hospital admissions for cellulitis and sepsis. For example, one English survey, reported in the Quarterly Journal of Medicine, records that 29% of lymphoedema patients had experienced at least one acute infection in the affected area. Of those experiencing acute infections, 27% were admitted for intravenous antibiotics. Over the duration of their oedema, 15% had experienced at least one hospital admission for their oedema. The mean length of hospital stay was 12 days, with an estimated cost of hospital stay of £2300.

9.2. In addition, more effective management of lymphoedema patients should reduce the input of pain management, tissue viability and skin breakdown. Appropriately managed patients should also have a better quality of life, thus increasing ability to work and reducing the level of associated disability benefits. The Quarterly Journal of Medicine study reports that over 80% of patients in the study had taken time off work due to their oedema, with an estimated mean time off work of 10.5 days for medical appointments. Overall, 9% stated that the oedema affected their employment status, with 2% of patients having to change jobs because of their oedema and 8% having to give up work because of it.

Capital requirements

9.3. Capital resources may be necessary to ensure that the specialist lymphoedema units provide adequate space for privacy during consultations and treatment.

9.4. Expenditure may be necessary to provide multi-professional clinics with equipment such as Doppler scanners and simple limb volume measurement calculators.

9.5. Boards are asked to undertake an analysis of the capital costs associated with the provision of lymphoedema clinics within the specialist lymphoedema networks.
IT requirements

9.6. Appropriate IT facilities should be made available to promote minimum data sets, link with other databases and facilitate audit. The costs of establishing and running the database can be determined following the discussions between the Department, Boards and Trusts.

Skill mix - Current practitioners

9.7. In relation to current staffing, responses from Trusts on service provision indicated that 14 physiotherapists have received some accredited training in lymphoedema. Responses also indicate that 2 Macmillan nurse specialists are trained in the management of lymphoedema patients and that some breast care specialist nurses have received introductory training in lymphoedema care. In addition, responses from Trusts identified 31 staff with general key worker skills in lymphoedema.

9.8. It is important to appreciate that in Northern Ireland not all of the specialist staff already trained in lymphoedema are WTE and currently practising their skills. Some have not been able to commence lymphoedema treatment and management because of other work commitments. In addition, the recommended model for lymphoedema clinics should provide daily lymphoedema services. The survey of HPSS provision concludes that daily lymphoedema clinics are only provided at Belvoir Park Hospital. Elsewhere, specialist practitioners provide clinics on a weekly, fortnightly or ad hoc basis.

Future skill mix

9.9. In order to provide a high standard of lymphoedema care, Chapter 8 has recognised that the number of specialist lymphoedema practitioners and other team members will need to be increased. As service provision is currently sparse or patchy, the Review Group has recommended the appointment of 6 WTE specialist lymphoedema practitioners, who would assume responsibility for quality, audit and education programmes, as well as clinical activity, and 9 WTE lymphoedema practitioners. These practitioners would be part of the specialist lymphoedema network, working from the specialist lymphoedema clinics and locality clinics as appropriate. The recruitment of these 15 staff would help to ensure adequate cover arrangements and enable provision to be made for continuing professional development of the practitioners' lymphoedema skills.

9.10. The Review Group has recommended that a consultant medical practitioner should develop a specialist interest in lymphoedema patients. It is recommended that a consultant should provide one weekly session at the specialist and the local clinics.
9.11. In addition, the Review Group has concluded that the models of service at the specialist lymphoedema units should be adequately supported by administrative staff. The Group has recommended that 6 WTE clerical administrative staff should be recruited to cover the specialist clinics at the cancer centre and cancer units. In particular, the administrative staff will be responsible for the operation of the Register of Lymphoedema Patients.

9.12. Additional costs will also be incurred with the recruitment of 6 WTE health care assistants to help specialist lymphoedema practitioners with more general tasks, such as helping patients dress and undress, cleaning couches, rolling bandages and having equipment available, so as to free up more of the specialist practitioners’ time.

Project Manager

9.13. Further costs will be associated with the appointment of a Project Manager for two years to take forward the development of lymphoedema services in line with the proposals in this report.

Education and training

9.14. A high quality model of lymphoedema care must also be supported by key workers in primary and secondary care. Resources will be required for education programmes for other health professionals, including primary care teams and cancer services teams. Appropriately trained district and practice nurses and GPs will have an important role in primary care whilst staff in cancer teams, including cancer specialist nurses and palliative care nurses, could help to meet the need in secondary care.

Compression garments

9.15. Adequate funding for compression garments and hosiery will also be essential. In relation to spending per patient, estimates quoted in the Welsh Review of Lymphoedema Services’ range from £48-£112 for staff and £50-£81 for garments, with staff time per patient ranging from one hour to 30 hours. These estimates would impact significantly on the demands of staff time and on the types of compression garments, bandages and dressings. Compression garments are not available on prescription although some bandages and dressings are.
9.16. The estimates of potential revenue resources required to develop lymphoedema services in Northern Ireland are shown in the table below.

<table>
<thead>
<tr>
<th>Revenue requirements</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 WTE Specialist Lymphoedema Practitioners</td>
<td>240,000</td>
</tr>
<tr>
<td>9 WTE Lymphoedema practitioners</td>
<td>288,000</td>
</tr>
<tr>
<td>6 WTE Clerical Assistants</td>
<td>78,000</td>
</tr>
<tr>
<td>6 WTE Healthcare Assistants</td>
<td>60,000</td>
</tr>
<tr>
<td>Consultant medical specialist input</td>
<td>120,000</td>
</tr>
<tr>
<td>Project Manager</td>
<td>50,000</td>
</tr>
<tr>
<td>Compression garments</td>
<td>293,410</td>
</tr>
<tr>
<td>Education and training</td>
<td>100,000</td>
</tr>
<tr>
<td>Patient information and support programme</td>
<td>30,000</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1,259,410</strong></td>
</tr>
</tbody>
</table>

9.17. The Review Group has recommended that each Health and Social Services Board should undertake a training needs analysis to determine the training required to enable the implementation of appropriate lymphoedema services along the lines of the proposals in this Report. The associated costs can be determined as part of this process.
CHAPTER 10
# ACTION PLAN

<table>
<thead>
<tr>
<th>Timescale</th>
<th>Tasks</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 months to 3 years</td>
<td>Establishment of Dedicated Specialist Lymphoedema Networks Development of Local Lymphoedema Networks</td>
<td>Trusts, primary care Trusts, hospices, primary care</td>
</tr>
<tr>
<td>18 months to 5 years</td>
<td>Specialist Training Programme Generalist Training Programme Patient information and support programme</td>
<td>Trusts Trusts, Primary Care, hospices and other healthcare professionals Trusts and primary care, hospices</td>
</tr>
<tr>
<td>5 years</td>
<td>Audit of Lymphoedema services, including user satisfaction</td>
<td>Boards and Trusts</td>
</tr>
</tbody>
</table>
EQUALITY IMPACT ASSESSMENT

Introduction

11.1. Section 75 of the Northern Ireland Act 1998 requires the Department of Health, Social Services and Public Safety (DHSSPS) in carrying out its functions relating to Northern Ireland, to have due regard to the need to promote equality of opportunity -

- between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- between men and women generally;
- between persons with a disability and persons without; and
- between persons with dependants and persons without.

11.2. In addition, without prejudice to the above obligation, DHSSPS must also, in carrying out its functions relating to Northern Ireland, have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group.

11.3. Consequently, each public authority is required to:

- Review its policies and procedures to determine whether there is any adverse or differential impact as regards equality of opportunity in relation to any of the Section 75 groups;
- Make changes to address any identified adverse or differential inequalities; and
- Consider new ways of working to promote equality of opportunity among the Section 75 groups.

11.4. An Equality Impact Assessment (EQIA) is a thorough and systematic analysis of a policy to determine the extent of differential impact upon the relevant groups and, in turn whether that impact is adverse. Adverse impact is where it has a negative impact on groups or individuals in relation to one or more of the Section 75 groups. The DHSSPS has identified the development of lymphoedema services as a new policy requiring EQIA.
Aim of the Lymphoedema Services Review

11.5. The proposals in the Review of Lymphoedema Services aim to improve the health and well being of people with lymphoedema in Northern Ireland. Proposals for the establishment of the specialist lymphoedema network aim to ensure that all patients with lymphoedema in Northern Ireland receive cost effective, equitable and high quality services, based on the best evidence available. In developing recommendations, the Review Group took the views of users into account.

Consideration of Available Data

11.6. The impact of the Lymphoedema Review’s proposals on Section 75 equality groups was considered in the EQIA. Statistical data on the nine equality groups was requested from the DHSSPS Information and Analysis Unit. An analysis of the quantitative data available focused on the accessibility of the nine different equality groups to the proposed model of care. Under the proposed model of care, specialist lymphoedema clinics would be provided at Belfast City, Altnagelvin, Antrim, Craigavon and the Ulster Hospitals. However, it should be noted that the Review also recommends that commissioners should work towards the provision of more local services, for example at local hospitals or treatment centres or hospices. This would make lymphoedema services even more accessible for people with lymphoedema.

Data Sources

11.7. A breakdown of the data sources is summarised below.

Census of population

11.8. A census of population is normally taken every ten years and is carried out by the Census Office for Northern Ireland. The census provides essential statistical information about the population and households for all parts of the country. The 2001 Census of Population provided numerical data at Census Output Area (COA) level in respect of the majority of the nine equality categories (or suitable proxies for the groups). For the “Persons with dependants” category, two sources were used: people who provide unpaid care and households with dependent children. Unpaid care in this context is defined as looking after, giving help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability or problems relating to old age. Unfortunately, no information was available on political preference or sexual orientation.
Table 1: Summary of Data Source by Equality Group

<table>
<thead>
<tr>
<th>Equality Group</th>
<th>Source of Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Northern Ireland 2001 Census Usualy Resident Population (Table KS01)</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Northern Ireland 2001 Census Marital Status - All persons aged 16 and over (Table KS04)</td>
</tr>
<tr>
<td>Religious Belief</td>
<td>Northern Ireland 2001 Census Community Background: Religion or Religion brought up in (Table KS07b)</td>
</tr>
<tr>
<td>Persons with/without Dependants</td>
<td>Northern Ireland 2001 Census Households With Dependent Children (Table KS21) Persons who provide unpaid care (Table KS08)</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>No data available</td>
</tr>
<tr>
<td>Age</td>
<td>Northern Ireland 2001 Census Age Structure (Table KS02)</td>
</tr>
<tr>
<td>Political Opinion</td>
<td>No data available</td>
</tr>
<tr>
<td>Persons with/without a Disability</td>
<td>Northern Ireland 2001 Census Persons with limiting long-term illness (Table KS08)</td>
</tr>
<tr>
<td>Ethnic Group</td>
<td>Northern Ireland 2001 Census Ethnic Group (Table KS06)</td>
</tr>
</tbody>
</table>

11.9. Once the data sets were assembled at COA, it was then possible to find the equality group composition of COAs which are furthest away from the proposed model of services and compare this composition to that of Northern Ireland as a whole.
11.10. People with lymphoedema are mainly treated as outpatients but some patients with lymphoedema may be admitted to hospital with complications such as cellulitis or septicamia. Others may be admitted to hospital for assessment of their condition.

11.11. The Hospital Inpatients System (HIS) processes information relating to inpatient stays in hospital. The source information for HIS is the Patient Administration System (PAS), which is maintained in all acute hospital sites in Northern Ireland. The HIS provided data on lymphoedema inpatients over the period 1998-2003 and was a source for informing the patient equality profile in relation to age, gender and marital status. Lymphoedema patients were selected from the HIS using the following ICD codes: 189.0 (lymphoedema), Q82.0 (hereditary lymphoedema) and I97.8 (post mastectomy and surgical).

Service configuration

11.12. The aim of the Lymphoedema Review is to improve the current provision of services for people with lymphoedema. Lymphoedema services have been provided on a very limited or non-existent basis, though this must not deflect from the dedication and commitment of health professionals currently providing such services as exist. The Review’s recommendations aim to extend the current delivery of services and to provide equality of access to services for people with both primary and secondary lymphoedema, regardless of where they live. The recommendation for the establishment of the specialist lymphoedema network, with specialist clinics at Belfast City, Ulster, Altnagelvin, Antrim and Craigavon Hospitals, aims to ensure equality of access for people with lymphoedema in each Health and Social Services Board area. In addition to the specialist lymphoedema clinics, it is proposed that commissioners should work towards the provision of more local services, for example at local hospitals or treatment centres or hospices.

Access to proposed specialist lymphoedema clinics

11.13. Access times from the centre of each Census Output Area (COA) by road to the proposed specialist lymphoedema clinics were calculated using the NMG package based on work using the Microsoft MapPoint software. This has been developed by Tony Hindle to update the Simplified Modelling of Spatial Systems (SMOSS) model, which was used to inform a rurality adjustment in the Health and Social Services Boards’ capitation formula and was subsequently adapted for the Northern Ireland Ambulance Service Strategic Review.
11.14. The location of the specialist lymphoedema clinics at Belfast City, Antrim, Ulster, Altnagelvin and Craigavon Hospitals have been mapped below and COAs have been shaded according to their access time to this configuration. It can be seen that all of Fermanagh, South Tyrone and parts of South Down and the North Antrim coast would be over 60 minutes from services under this configuration. This area contains over 90,000 people representing about 5% of the Northern Ireland population. On the other hand, over 50% of the Northern Irish population would be less than 20 minutes from services.

**Figure 1: Access times by Census Output Area**

**Access to services - general methodology**

11.15. Using the census data for each COA, the equality group composition of each of the three access time ranges, set out at Figure 1 above, was then determined. An analysis of the results, together with data from the Hospital Inpatients System, is discussed below.

**Between men and women generally - Gender:**

11.16. From the Hospital Inpatients System, it was possible to determine the gender of patients with lymphoedema over the years 1998 – 2003. Table 2 below shows that over two-thirds (71%) of lymphoedema patients are female.
Table 2 – Lymphoedema patients by gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>111</td>
<td>29%</td>
</tr>
<tr>
<td>Female</td>
<td>276</td>
<td>71%</td>
</tr>
<tr>
<td>Total</td>
<td>387</td>
<td>100%</td>
</tr>
</tbody>
</table>

11.17. As lymphoedema is more common following treatment of cancers more common in women, secondary lymphoedema is, therefore, more common in women than in men. This is in keeping with the higher usage of lymphoedema services by women in the above table.

11.18. An analysis of the gender equality group composition of each of the access time ranges to the nearest proposed lymphoedema clinic is shown at Table 3 below.

Table 3 – Gender Equality Group Composition by Access Time Range

<table>
<thead>
<tr>
<th>Access Time</th>
<th>Males</th>
<th>Females</th>
<th>All Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>48%</td>
<td>52%</td>
<td>100%</td>
</tr>
<tr>
<td>20 - 40</td>
<td>50%</td>
<td>50%</td>
<td>100%</td>
</tr>
<tr>
<td>40 - 60</td>
<td>49%</td>
<td>51%</td>
<td>100%</td>
</tr>
<tr>
<td>Over 60</td>
<td>50%</td>
<td>50%</td>
<td>100%</td>
</tr>
</tbody>
</table>

This analysis found that the gender composition for these access ranges was approximately the same as the composition of the Northern Ireland population. This would, therefore, indicate that there is no differential impact for the equality category of gender under these proposed service configurations.

Persons of different age:

11.20. Again, the Hospital Inpatients System was used to consider the age ratio of lymphoedema inpatients. An analysis of the data from 1998 – 2003 on the age of patients is shown below in Table 4.
Table 4 – Lymphoedema patients by age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-17</td>
<td>12</td>
<td>3%</td>
</tr>
<tr>
<td>18-64</td>
<td>135</td>
<td>35%</td>
</tr>
<tr>
<td>65+</td>
<td>240</td>
<td>62%</td>
</tr>
<tr>
<td>Total</td>
<td>387</td>
<td>100%</td>
</tr>
</tbody>
</table>

11.21 Lymphoedema is more common in adults than in children. The above Table shows that almost two-thirds of lymphoedema inpatients are 65 years of age or over (62%), which is in keeping with the incidence of the condition.

11.22 An analysis of the age equality group composition of each of the access time ranges is given below at Table 5.

Table 5 – Hospital Inpatients System – Age of Lymphoedema Patients

<table>
<thead>
<tr>
<th>Access Times (Minutes)</th>
<th>Persons Under 18</th>
<th>Persons Aged 18-64</th>
<th>Persons Aged 65+</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>26%</td>
<td>60%</td>
<td>14%</td>
<td>100%</td>
</tr>
<tr>
<td>20 – 40</td>
<td>28%</td>
<td>60%</td>
<td>12%</td>
<td>100%</td>
</tr>
<tr>
<td>40 – 60</td>
<td>28%</td>
<td>59%</td>
<td>13%</td>
<td>100%</td>
</tr>
<tr>
<td>Over 60</td>
<td>28%</td>
<td>58%</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>Northern Ireland Age Composition</td>
<td>27%</td>
<td>60%</td>
<td>13%</td>
<td>100%</td>
</tr>
</tbody>
</table>

11.23 This analysis found that these age equality group composition across access times ranges were approximately the same as the composition of the Northern Ireland population. This would, therefore, indicate that there is no differential impact for the equality category of age.

Lymphoedema Patients (aged 16+) by marital status

11.24 The marital status of lymphoedema patients aged 16 years or over was captured by the Hospital Inpatients System data covering the period 1998 – 2003 as follows.
Table 6 – Hospital Inpatient System – Marital Status of Lymphoedema Inpatients

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Divorced</td>
<td>11</td>
<td>3%</td>
</tr>
<tr>
<td>Married/Separated</td>
<td>143</td>
<td>38%</td>
</tr>
<tr>
<td>Not known</td>
<td>34</td>
<td>9%</td>
</tr>
<tr>
<td>Single</td>
<td>67</td>
<td>18%</td>
</tr>
<tr>
<td>Widowed</td>
<td>121</td>
<td>32%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>376</td>
<td>100%</td>
</tr>
</tbody>
</table>

11.25. An analysis of the marital status equality group composition of each of the access time ranges at Figure 1 is given below at Table 7.

Table 7 - Marital Status Equality Group Composition by Access Time Range for All Persons Aged 16 and Over

<table>
<thead>
<tr>
<th>Access Times (Minutes)</th>
<th>Single (Never Married)</th>
<th>Married/Remarried</th>
<th>Divorced/Widowed/Separated</th>
<th>All Persons Aged 16 and Over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>34%</td>
<td>49%</td>
<td>17%</td>
<td>100%</td>
</tr>
<tr>
<td>20 – 40</td>
<td>31%</td>
<td>55%</td>
<td>14%</td>
<td>100%</td>
</tr>
<tr>
<td>40 – 60</td>
<td>33%</td>
<td>53%</td>
<td>14%</td>
<td>100%</td>
</tr>
<tr>
<td>Over 60</td>
<td>34%</td>
<td>53%</td>
<td>13%</td>
<td>100%</td>
</tr>
<tr>
<td><strong>NI Marital Status Composition%</strong></td>
<td>33%</td>
<td>51%</td>
<td>16%</td>
<td>100%</td>
</tr>
</tbody>
</table>

11.26. It is recognised that for Marital Status the proportion of Married/Remarried people in the 20 to 40 range (55%) is slightly greater than the Northern Ireland proportion (51%). However, in general, the marital status composition under the range of access times is approximately the same as the composition of the Northern Ireland population. This would, therefore, indicate that there is little differential impact for the equality category of marital status.
Persons With/Without Disability Equality Category

11.27. An analysis of the Persons With/Without a Disability equality category was carried out for each of the access time ranges. This would indicate that there is no differential impact for this equality group composition as shown below in Table 8.

Table 8 - Persons With/Without a Disability

<table>
<thead>
<tr>
<th>Access Time (Minutes)</th>
<th>Persons With Limiting Long Term Illness</th>
<th>Persons Without Limiting Long Term Illness</th>
<th>All Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>21%</td>
<td>79%</td>
<td>100%</td>
</tr>
<tr>
<td>20-40</td>
<td>19%</td>
<td>81%</td>
<td>100%</td>
</tr>
<tr>
<td>40 – 60</td>
<td>20%</td>
<td>80%</td>
<td>100%</td>
</tr>
<tr>
<td>Over 60</td>
<td>19%</td>
<td>81%</td>
<td>100%</td>
</tr>
<tr>
<td>NI Disability Composition</td>
<td>20%</td>
<td>80%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Persons With/Without Dependents

11.28. An analysis of the Persons With/Without Dependents Equality Group Composition shows little variation across access time ranges. This is illustrated in Table 9 below, for Persons with Dependent Children.

Table 9 – Persons With/Without Dependents

<table>
<thead>
<tr>
<th>Access Time (Minutes)</th>
<th>With dependent children</th>
<th>Without dependent children</th>
<th>All Households</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>35%</td>
<td>65%</td>
<td>100%</td>
</tr>
<tr>
<td>20-40</td>
<td>39%</td>
<td>61%</td>
<td>100%</td>
</tr>
<tr>
<td>40 – 60</td>
<td>39%</td>
<td>61%</td>
<td>100%</td>
</tr>
<tr>
<td>Over 60</td>
<td>39%</td>
<td>61%</td>
<td>100%</td>
</tr>
<tr>
<td>Northern Ireland Composition</td>
<td>36%</td>
<td>64%</td>
<td>100%</td>
</tr>
</tbody>
</table>
11.29. An analysis of the data for Persons Providing Unpaid Care for Dependents was also carried out. Unpaid care in this context is defined as looking after, giving help or support to family members, friends, neighbours or others because of long term physical, mental health or disability or problems relating to old age. The analysis at Table 10 below shows no potential differential impact for Persons providing unpaid care for Dependents.

**Table 10: Persons Providing Unpaid Care for Dependents**

<table>
<thead>
<tr>
<th>Access Time (Minutes)</th>
<th>All Persons who Provide Unpaid Care</th>
<th>All Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>12%</td>
<td>100%</td>
</tr>
<tr>
<td>20-40</td>
<td>11%</td>
<td>100%</td>
</tr>
<tr>
<td>40-60</td>
<td>10%</td>
<td>100%</td>
</tr>
<tr>
<td>Over 60</td>
<td>10%</td>
<td>100%</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>11%</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Community Background Equality Group Category**

11.30. The following table illustrates the breakdown by community background.

**Table 11: Community Background**

<table>
<thead>
<tr>
<th>Access Time (Mins)</th>
<th>Catholic</th>
<th>Protestant and other Christian</th>
<th>Other religions and philosophies</th>
<th>None</th>
<th>All Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>38%</td>
<td>58%</td>
<td>1%</td>
<td>3%</td>
<td>100%</td>
</tr>
<tr>
<td>20-40</td>
<td>46%</td>
<td>51%</td>
<td>1%</td>
<td>2%</td>
<td>100%</td>
</tr>
<tr>
<td>40-60</td>
<td>57%</td>
<td>41%</td>
<td>0%</td>
<td>2%</td>
<td>100%</td>
</tr>
<tr>
<td>Over 60</td>
<td>56%</td>
<td>43%</td>
<td>0%</td>
<td>1%</td>
<td>100%</td>
</tr>
<tr>
<td>Northern Ireland composition</td>
<td>44%</td>
<td>53%</td>
<td>0%</td>
<td>3%</td>
<td>100%</td>
</tr>
</tbody>
</table>
11.31. From the above analysis of Community Background category, Catholics would appear to be over represented in those ranges farther from services. For example, 56% of those living in the “Over 60 minutes” range are Catholic yet only 44% of the Northern Ireland population are Catholic. In contrast, 43% of those living in the “Over 60 minutes” range are Protestant while this community accounts for 53% of the total population.

11.32. Further analysis shows that only 5.3% of the Northern Ireland population fall within the “Over 60 minutes” category. However, this equates to around 90,000 people living in Fermanagh, South Tyrone and parts of South Down and North Antrim. Whilst only a small number of these people will require lymphoedema services, it is nevertheless recognised that a greater percentage of Catholics (7%) than Protestants (4%) are over 60 minutes away from the specialist lymphoedema clinics. It should, however, be emphasised that the proposed model of services would nevertheless provide reasonably easy access to the majority of the Catholic community in that 75% are less than 40 minutes from services.

11.33. The Review Group has, nonetheless, concluded that commissioners should consider the development of lymphoedema services at local hospitals, local treatment centres or hospices to make services more accessible to these parts of Northern Ireland in particular. The Review Group welcomes the provision of some local lymphoedema services at Tyrone County and the Erne Hospitals which should lessen the potential adverse impact of the proposals on “community background/religion” equality category.

**Ethnic Composition**

11.34. An analysis of the ethnic group composition of each time range is not very informative as it is generally 99% “White”. Instead, Table 12 below shows the percentages of each ethnic group in each range of access times. It can be seen that the proportions of all ethnic groups except “Irish Travellers” and “Other Black” less than 20 minutes from services are larger than that of the “White” majority. Furthermore, the proportion of the “Other Black” (82%) ethnic group less than 40 minutes from services is virtually identical to the proportion of the “White” group. Also, the 2001 Census recorded a total of 1,715 Irish travellers in Northern Ireland making the number over 40 minutes from services very small (380 in total).
Table 12: Proportions of each ethnic group in each time range

<table>
<thead>
<tr>
<th>Access time (mins)</th>
<th>All persons</th>
<th>White</th>
<th>Irish Traveller</th>
<th>Mixed</th>
<th>Indian</th>
<th>Pakistani</th>
<th>Bangladeshi</th>
<th>Other Asian</th>
<th>Black Caribbean</th>
<th>Black African</th>
<th>Other Black</th>
<th>Chinese</th>
<th>Other Ethnic Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>54%</td>
<td>54%</td>
<td>46%</td>
<td>64%</td>
<td>73%</td>
<td>86%</td>
<td>83%</td>
<td>80%</td>
<td>66%</td>
<td>71%</td>
<td>46%</td>
<td>72%</td>
<td>70%</td>
</tr>
<tr>
<td>20 to 40</td>
<td>27%</td>
<td>27%</td>
<td>31%</td>
<td>21%</td>
<td>14%</td>
<td>9%</td>
<td>10%</td>
<td>11%</td>
<td>16%</td>
<td>15%</td>
<td>36%</td>
<td>17%</td>
<td>19%</td>
</tr>
<tr>
<td>40 to 60</td>
<td>14%</td>
<td>14%</td>
<td>16%</td>
<td>11%</td>
<td>12%</td>
<td>4%</td>
<td>4%</td>
<td>7%</td>
<td>17%</td>
<td>10%</td>
<td>15%</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>Over 60</td>
<td>5%</td>
<td>5%</td>
<td>7%</td>
<td>4%</td>
<td>1%</td>
<td>1%</td>
<td>3%</td>
<td>2%</td>
<td>1%</td>
<td>4%</td>
<td>3%</td>
<td>2%</td>
<td>3%</td>
</tr>
</tbody>
</table>

11.35. No data was available for persons of different sexual orientation.

Persons of different political opinion

11.36. No data was available for persons of different political opinion.

Conclusion

11.37. A summary of the potential equality impact of the proposals for the development of specialist lymphoedema clinics under the configuration of services at Belfast City, Altnagelvin, Antrim, Craigavon and the Ulster Hospitals, is shown at Table 13 below.

Table 13: Summary of the Likely Impact on Equality Groups

<table>
<thead>
<tr>
<th>Equality Group</th>
<th>Likelihood of impact on Equality Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>No differential impact</td>
</tr>
<tr>
<td>Age</td>
<td>No differential impact</td>
</tr>
<tr>
<td>Marital Status</td>
<td>No differential impact</td>
</tr>
<tr>
<td>Community Background/Religion</td>
<td>Potential differential impact</td>
</tr>
<tr>
<td>Persons with/without disability</td>
<td>No differential impact</td>
</tr>
<tr>
<td>Persons with/without dependents</td>
<td>No differential impact</td>
</tr>
<tr>
<td>Ethnic Group</td>
<td>No differential impact</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>No data available</td>
</tr>
<tr>
<td>Political opinion</td>
<td>No data available</td>
</tr>
</tbody>
</table>
11.38. In reaching its conclusions, the Lymphoedema Review Group has considered the potential impact which the proposals may have on the nine equality groups. On the whole, the implementation of the Review will not have a potential negative impact on the nine equality groups, with the exception of a potential adverse impact on the category of “community background/religion” as shown in the above table.

11.39. In relation to this, this EQIA recommends that commissioners should take action to develop the specialist lymphoedema network to provide easier access to people living in Fermanagh, South Tyrone and parts of South Down and North Antrim in particular. This could be done by providing lymphoedema services at local hospitals, local treatment centres or hospices. The EQIA welcomes the provision of some local lymphoedema services at Tyrone County and the Erne Hospitals, solely to address the issue of travelling times, which should lessen the potential adverse impact of the proposals on “community background/religion” equality category.

11.40. The implementation of the Review's recommendations will have a positive impact for the majority of people in Northern Ireland because lymphoedema services have only been provided on a very limited or non-existent basis in many areas. For example, proposals for the establishment of the specialist lymphoedema network, the appointment of additional staff and the provision of appropriate workspace and equipment will help to improve the quality and speed of access to care for all lymphoedema patients who need lymphoedema services regardless of whether their condition is primary or secondary, or where they live.

11.41. Further, the Implementation Group will monitor the impact of services development on the different equality groups and commissioners will be required to develop lymphoedema services in line with equality requirements. In addition, the development of a Lymphoedema Patient Register will be a means of monitoring equality issues in relation to the future provision of lymphoedema services. By these means, it is concluded that the equality requirements will be met appropriately.
LYMPHOEDEMA STEERING GROUP: MEMBERSHIP APPENDIX 1

Angela Garvey (Chair), Consultant in Palliative Care, Altnagelvin Hospital
Jackie Clarke, Oncologist, Belvoir Park Hospital
Wilma Compton, Person with Lymphoedema
Stephen Dobbs, Gynaecological Cancer Surgeon, Belfast City Hospital
Shauna Fannin, General Practitioner, Ballymoney Health Centre
Paula Fearon, Breast Care Nurse, Craigavon Area Hospital Group Trust
Hilary Jenkinson, Dermatologist, Antrim Area Hospital
Bernard Lee, Vascular Surgeon, Belfast City Hospital
Maria Magee, District Nurse, Eglinton Health Centre
Adrian Mairs, Public Health Medicine, Northern Health and Social Services Board Services Board
Caroline Mason, Public Health Medicine, Western Health and Social Services Board
Liz Mitchell, Department of Health, Social Services and Public Safety
Olive McCann, Membership Lymphoedema Support Group
Cliona McCotter, Senior Physiotherapist, Belfast City Hospital
Margaret Napier, Senior Physiotherapist, NI Hospice
Anne O’Hagan, Palliative Care Nurse, Antrim Area Hospital
Breige O’Kane, Membership Lymphoedema Support Group
Jane Rankin, Superintendent Physiotherapist, Belfast City Hospital
Sigi Refsum, Breast Cancer Consultant Surgeon, Belfast City Hospital
Rosemary Scott, Department of Health, Social Services and Public Safety
Anne Treanor, Macmillan Breast Care Nurse, Ulster Hospital
Michael Young, Consultant Urologist, Craigavon Area Hospital
Mary Waddell, Director of Nursing, Eastern Health and Social Services Board
LYMPHOEDEMA PATIENT PATHWAY

ACCESS TO

HEALTH CARE PROFESSIONAL FOR ADVICE ON RISK REDUCTION AND WHAT TO DO IF OEDEMA OCCURS

(cg SPECIALIST CANCER NURSE PRIMARY CARE TEAM)

OEDEMA DEVELOPS

ACCESS TO SPECIALIST MULTI-DISCIPLINARY LYMPHOEDEMA SERVICE FOR DIAGNOSIS ASSESSMENT OF OEDEMA AND QUALITY OF LIFE ASSESSMENT INVESTIGATION REGISTRATION

TREATMENT PLAN

SPECIALIST PRACTITIONER

TREATMENT OF OEDEMA

ACCESS TO DLT/CDT FOR TREATMENT OF LYMPHOEDEMA INTENSIVE AND MAINTENANCE THERAPY AS REQUIRED

REVIEW AT LYMPHOEDEMA CLINIC

LONG TERM SELF MAINTENANCE CARE

ACCESS TO COMPRESSION GARMENTS AND TOP UP DLT/CDT AS REQUIRED AND SELF AND HEALTH PROFESSIONALS AWARE OF CONTINUED RISK REDUCTION STRATEGIES

LONG TERM FOLLOW UP MAINTENANCE

CONTINUED FOLLOW UP AT SPECIALIST CLINIC FOR COMPLEX PROBLEMS (FREQUENT CDT/DLT FOR MAINTENANCE COMPLEX MADE TO MEASURE GARMENTS)
- Refers to service or providers of Lymphoedema services or linked services

- Underpinning regional and local networks to support standards of care and treatment.
LYMPHOEDEMA SPECIALIST PRACTITIONER

APPENDIX 4

Role of post

The postholder will be the designated specialist lymphoedema practitioner responsible for the overall co-ordination, management and evaluation of interventions of lymphoedema care.

The postholder will act in a consultative capacity, establishing and maintaining close liaison with all members of the Board’s lymphoedema network. The postholder will be responsible for facilitating and promoting standard setting in the lymphoedema network.

Main duties/responsibilities

Clinical

Demonstrate clinical excellence and a high standard of practice in the field of lymphoedema.

Be responsible for the organisation, co-ordination and management of caseload/client group.

Act in a consultative capacity with all network practitioners.

Work with the specialist network to ensure all aspects of patient care are met, facilitating good interdisciplinary communications and co-operation.

Within the network to ensure the facilitation of definition and agreement of standards for lymphoedema care and monitor the effectiveness of those standards.

Ensure that patients with lymphoedema, after standardised assessment, are referred to the appropriate practitioner.

Liaise with medical staff and other disciplines in the management of patients’ lymphoedema care so as to achieve a co-ordinated specialist service.

Ensure the confidentiality of information received about patients and the care they are to receive at all times.

Advise and offer support to patients, relatives and staff caring for patients with lymphoedema.

Actively promote audit and research in lymphoedema management.
Maintain accurate records of patients whenever/wherever they have been seen and document all information in their multi-disciplinary care plan and lymphoedema file.

Be responsible for the Board’s lymphoedema register.

**Management**

In conjunction with the directorate clinical managers, manage the budget for lymphoedema within the limits set by commissioners

Oversee the selection and use of appropriate equipment and other resources regarding lymphoedema

Ensure the entry of all patients into a lymphoedema register

Monitor services provided, collect and maintain statistical information.

Submit written reports as requested.

Maintain awareness of current developments in lymphoedema services and the implications these may have on care, expenditure etc.

Utilise research findings in the delivery of specialist services and disseminate relevant information to staff.

Act as the patients’ advocate in the matters relating to care, treatment and welfare and bring any real or perceived unmet needs to the attention of appropriate practitioners.

**General management**

Attend MDT meetings as required.

Develop and participate in the Northern Ireland Lymphoedema Network.

Ensure network meetings happen monthly, accessing teleconferencing facilities if necessary.

In collaboration with other colleagues, participate in the development of services for lymphoedema locally, nationally and internationally.

Create an environment where lymphoedema is advancing and innovative.
**Education/training**

Maintain a personal commitment to the expansion and development of professional skills and knowledge in the area of lymphoedema.

Liaise with in-service consortium, contributing to lymphoedema education programme.

Participate in the induction of new staff and participate in regular update training.

Advise on the promotion of health and palliative care, with particular emphasis on such advice linked to lymphoedema.
LYMPHOEDEMA PRACTITIONER

Role of post

The postholder will be the lymphoedema practitioner responsible for the assessment, management and evaluation of people with lymphoedema.

Main duties/responsibilities

Clinical

Demonstrate clinical excellence and a high standard of practice in the field of lymphoedema.

Organise, co-ordinate and manage caseload/client group.

Work with the specialist network to ensure all aspects of patient care are met, facilitating good interdisciplinary communications and co-operation.

Within the network to work to agreed standards for lymphoedema care and monitor the effectiveness of those standards.

Liaise with medical staff and other disciplines in the management of patients’ lymphoedema care so as to achieve a co-ordinated specialist service.

Ensure the confidentiality of information received about patients and the care they are to receive at all times.

Advise and offer support to patients, relatives and staff caring for patients with lymphoedema.

Participate in audit and research in lymphoedema management.

Maintain accurate records of patients whenever/wherever they have been seen and document all information in their multi-disciplinary care plan and lymphoedema file.

Ensure the entry of all patients into a lymphoedema register

Collect and maintain statistical information on patients treated.

Maintain awareness of current developments in lymphoedema services and the implications these may have on care, expenditure etc.

Utilise research findings in the delivery of specialist services.
Act as the patients’ advocate in the matters relating to care, treatment and welfare and bring any real or perceived unmet needs to the attention of appropriate practitioners.

Attend MDT meetings as required.

Participate in the Northern Ireland Lymphoedema Network.

Create an environment where lymphoedema is advancing and innovative.

**Education/training**

Maintain a personal commitment to the expansion and development of professional skills and knowledge in the area of lymphoedema.
LIST OF REFERENCES

1. Response to questionnaire from patient with lymphoedema.


3. Response to questionnaire from one of the HSS Trusts.


9. Response from person with lymphoedema.


30. Drugs and Therapeutics Bulletin 2003, 43-45


32. Dr Price, Belfast City Hospital Trust 2000/2001.

