

TEMPLATE FOR MANAGEMENT

Developing a lymphoedema service

MAKING THE CASE

SET UP AND DEVELOPMENT

ROLES

EVALUATION



Lymphoedema
Framework

LYMPHOEDEMA FRAMEWORK
AN INTERNATIONAL PERSPECTIVE

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Developing a lymphoedema service

CJ Moffatt

This practical document is part of the *Template* series and is designed to support healthcare professionals in setting up and developing much needed lymphoedema services.

In many countries, the provision of care for patients with lymphoedema is inadequate, often as a result of under-recognition of this chronic debilitating condition of highly diverse aetiology. Historical influences on service development have in some cases resulted in inequity for certain groups of patients and in approaches to healthcare provision that are not necessarily relevant today. Growing recognition that lymphoedema has causes other than cancer and recent changes in healthcare priorities necessitate a fresh approach to lymphoedema service provision.

The first paper in this document describes how to construct a lymphoedema service proposal that is founded on the Lymphoedema Framework Project's standards of practice for lymphoedema services¹ (Box 1). It stresses the use of local data to ensure that the proposed service is designed to meet local need. It also emphasises that the proposal should demonstrate how the service will integrate into the current healthcare system and support national health initiatives.

In the second paper, Hill and Davies draw on years of experience in the field of lymphoedema to provide highly relevant and useful advice on the practicalities of setting up and running a lymphoedema service.

The third paper examines the roles of those working in lymphoedema services. Sneddon reviews the influences on service development in the UK and the implications of initiatives to develop flexible career pathways. She then proposes role titles, components and educational requirements.

The final paper by Keeley and Franks stresses the vital role of service evaluation in ongoing service development and in securing funding. It describes different forms of evaluation and reviews health economics in relation to lymphoedema.

By providing clear guidance on how to secure funding and how to set up and run an effective and responsive lymphoedema service, this document aims to enhance provision of care and ensure equity of access for all patients affected by lymphoedema of whatever aetiology.

BOX 1 Standards of practice for lymphoedema services¹

Standard 1: Identification of people at risk of or with lymphoedema

Systems to identify people at risk of or with lymphoedema, regardless of cause, will be implemented and monitored to ensure that patients receive high quality education and lifelong care

Standard 2: Empowerment of people at risk of or with lymphoedema

Individual plans of care that foster self-management will be developed in partnership with patients at risk of or with lymphoedema (involving relatives and carers where appropriate), in an agreed format and language

Standard 3: Provision of lymphoedema services that deliver high quality clinical care that is subject to continuous improvement and integrates community, hospital and hospice based services

All people at risk of or with lymphoedema will have access to trained healthcare professionals, including lymphoedema specialists, who will work to agreed standards for comprehensive ongoing assessment, planning, education, advice, treatment and monitoring. Care will be of a high standard and subject to continuous quality improvement

Standard 4: Provision of high quality clinical care for people with cellulitis/erysipelas

Agreed protocols for the rapid and effective treatment of cellulitis/erysipelas, including prevention of recurrent episodes, will be implemented and monitored by healthcare professionals who have completed recognised training in this subject

Standard 5: Provision of compression garments for people with lymphoedema

Agreed protocols for assessment and the provision of compression garments for people with lymphoedema, or where warranted, those at risk of lymphoedema, will be implemented and monitored

Standard 6: Provision of multi-agency health and social care

Following comprehensive assessment, any patient at risk of or with lymphoedema who requires multi-agency support will have access to and receive care appropriate to their needs from health and social services

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Making the case for developing a lymphoedema service

PA Morgan¹, CJ Moffatt²

This paper provides practical guidance to healthcare professionals who want to develop and present a case for an integrated lymphoedema service. The text elaborates the key steps of a model for this process (Figure 1, page 3). Inevitably, the process of developing an effective case will involve recommending fundamental change for many people, including healthcare professionals and patients. It may also mean confronting often deeply held and traditional approaches to lymphoedema management and demonstrating that significant unmet need frequently exists.

The provision of lymphoedema services worldwide varies from very well developed care to virtually no provision. Many patients are not properly diagnosed and there is a pervasive impression that the condition is rare, causes few problems, is not life threatening and cannot be treated¹. However, without adequate treatment, lymphoedema can have major effects, including long-term disability, difficulties with work and emotional problems²⁻⁴. An integrated lymphoedema service ultimately aims to identify patients with swelling early so that treatment is timely and effective and enables patients to remain active and to self-manage their condition.

INFLUENCES ON SERVICE DEVELOPMENT

The belief that lymphoedema is only related to cancer has dominated the way that many lymphoedema services have developed. Indeed, in the UK, inequity exists for patients whose lymphoedema is not related to cancer because services that treat only cancer-related cases have been developed⁵. There is also evidence that lymphoedema/chronic oedema is poorly understood and that the number of non-cancer related cases within a range of healthcare specialties may be underestimated⁶.

Worldwide, however, increasing awareness of prevalence and the significant proportion of patients receiving inadequate or no care has prompted professional groups to lobby for effective services for all types of lymphoedema. The increasing and vitally important voice of patients demanding better care adds weight to the cause.

These factors are set against a backdrop of resource scarcity and rising numbers of people with chronic illness that is characterised by co-morbidity and complexity, increasing age-related prevalence and considerable resource burden⁷. Consequently, lymphoedema can be seen as

signposting the imperative to effectively manage neglected long-term conditions.

CONSULTATION AND PARTNERSHIP

A lone healthcare professional can rarely successfully develop a service single-handed. Ensuring the collaboration of key stakeholders (including patients), those with the authority to drive change and those who may feel threatened is vital in creating the shared vision that should underpin a new or expanded lymphoedema service (Box 1).

In the current environment of escalating healthcare costs and rationalisation of services, competition for resources is fierce. It is therefore essential to use national and local policy to support the case for a new lymphoedema service. For example, in the UK, an aim of current health policy is to reduce hospital admissions. This aim can be used to justify lymphoedema services that provide community-based care and reduce hospital admissions for cellulitis.

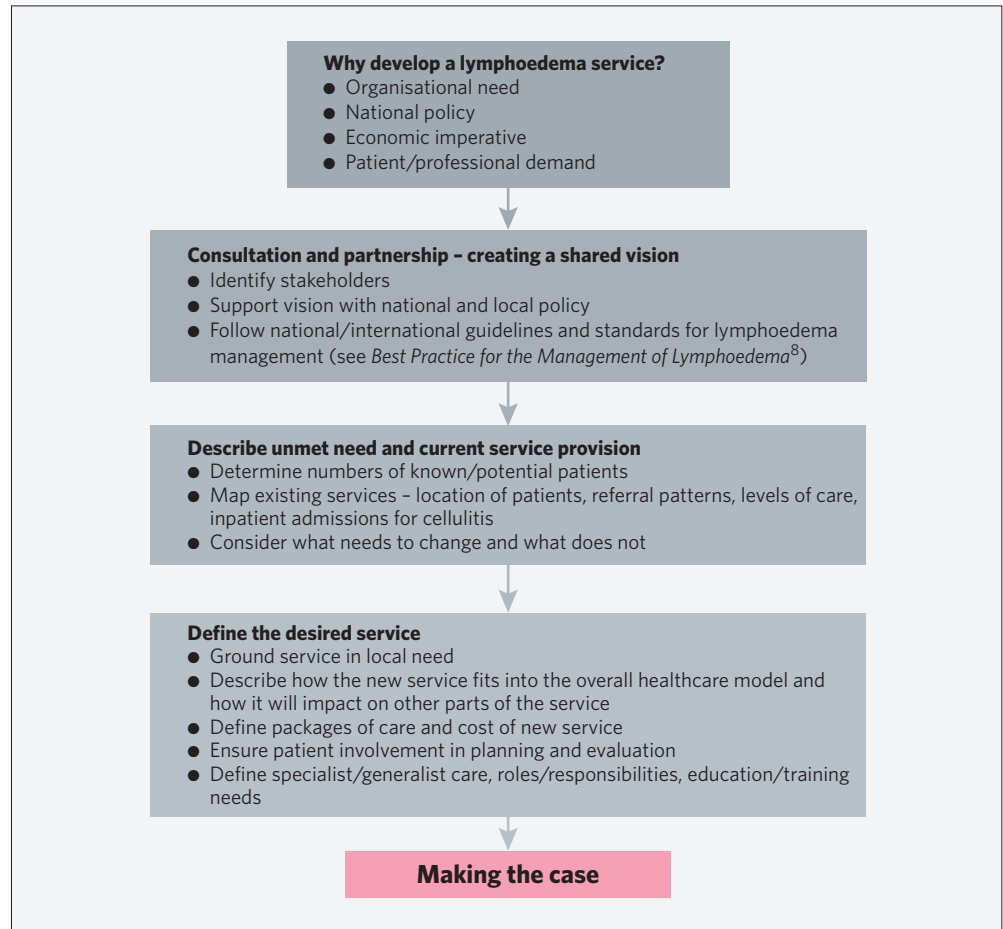
Definitions of primary/secondary lymphoedema and chronic oedema will be needed to ensure that all involved, especially

BOX 1 Possible stakeholders

- Healthcare organisations – eg local primary care management team
- Funding/commissioning/performance evaluation agencies
- Local managers
- Local lymphoedema practitioners
- Medical specialists
- Community/district/home care nursing teams
- Local health sector finance departments
- Physiotherapists, occupational therapists, podiatrists, pharmacists
- Patients, patient support groups, health service user groups
- National lymphology groups

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FIGURE 1 A model for making the case for development of a lymphoedema service



fundors and service commissioners, have a common understanding (Box 2). Such definitions will also highlight that affected patients may be found throughout the healthcare system.

DESCRIBING UNMET NEED

Describing unmet need requires more than emotive accounts of the suffering that accompanies lymphoedema. Unmet need can be demonstrated by defining discrepancies in the numbers of patients needing and receiving

treatment and deficiencies in service provision. In some countries, information technology systems are sufficiently developed to provide some indication of lymphoedema-related activity and cost data. However, because awareness of lymphoedema is often poor, the data collected may be limited in detail and scope.

Gathering and appraising information to provide a clear picture of the current situation is essential and should involve partnership with individuals and agencies that have the knowledge and skills necessary to undertake this critical component effectively.

Published data can be used to calculate how many people have lymphoedema/chronic oedema in a local area. However, prevalence may be influenced by local population demographics, eg age, and adjustments should be made accordingly³.

Prospective funding sources are likely to require locally derived data. Two complementary data collection processes can be used:

- patient identification
- service mapping.

Boxes 3 and 4 (page 4) detail how the information is gathered and outline the content of the forms

BOX 2 Definitions of lymphoedema and chronic oedema (adapted from^{3,9})

Primary lymphoedema

Arises from an intrinsic defect in lymph pathways. Can present at birth, in early childhood or in adult life. May be inherited. The term is often used when there is no identifiable external cause

Secondary lymphoedema

Results from damage to the lymphatic system, eg by treatment for cancer (surgery or radiotherapy), trauma, infection, inflammation and venous disease

Chronic oedema

Describes oedema that has been present for more than three months and that does not resolve with elevation and rest. Can be caused by a wide range of conditions, eg chronic heart failure, chronic venous hypertension, with secondary lymphatic failure

BOX 3 Process for patient identification and service mapping

Ideally, all healthcare professionals in the area to be served by a new or redeveloped lymphoedema service should be included. However, if necessary, particular healthcare settings or groups of healthcare professionals can be selected. Presentation of results should specify any limitations in the scope of the data collected.

Aims

To identify within a defined population or geographical area all people with lymphoedema/chronic oedema (defined as chronic swelling of more than three months' duration) affecting the arm, leg (with or without co-existing leg ulceration), torso (specifically breast and back), head and neck, and genitalia

To identify services and treatments currently being accessed by people with lymphoedema/chronic oedema

Method**Data sources**

Healthcare professionals from the following groups are contacted by letter and sent patient identification and service mapping data collection forms (Box 4) and a pre-paid addressed envelope. Non-responders are followed up one month from original contact by telephone or letter

Community services

- General practices
- District/community/home nursing services
- Lymphoedema services
- Hospices
- Community hospitals
- Day treatment services
- Community physiotherapy clinics
- Community occupational therapy clinics
- Prosthetic and orthotic services
- Leg ulcer specialist services
- Manual lymphatic drainage specialist services
- Lymphoedema patient support groups

Acute services

- Oncology/breast clinics
- Specialist assessment and treatment units
- Dermatology
- Care of the elderly
- Medical and surgical wards
- Palliative care services
- Vascular surgery services
- Paediatric services
- Physiotherapy services
- Occupational therapy services
- Podiatry

Patient identification

All patients with lymphoedema/chronic oedema are included irrespective of whether the professional completing the patient identification questionnaire (Box 4) is treating the oedema

A patient coding system is used to prevent double counting during data analysis, eg patient initials/date of birth (as ddmmyy)/gender. Mary Smith date of birth 29 March 1936 would have an identification code of MS290336F

Identification and assessment of people with chronic oedema within hospitals is best undertaken by site visits by the lead specialist and other appropriately trained staff

Mapping the current service

Healthcare professionals are asked to complete a service mapping questionnaire (Box 4)

Analysis

All data should be anonymised and analysed using descriptive methods, eg quantification or counting of responses in each category and subcategory within the questionnaires. From this, percentages can be calculated to provide the proportion of the total study population within a given category or subcategory. Wherever possible, assistance with data analysis should be sought from a statistician

BOX 4 Data collection form outlines

Examples of data collection forms used for patient identification and service mapping can be found at www.mep ltd.co.uk/publications.html. The types of data that should be collected are listed below. The use where possible of closed questions, lists of possible answers and tick boxes will encourage form completion and will aid data analysis.

Patient identification*

- Healthcare professional's contact details
- Personal details (including name and date of birth) and ethnic origin of person affected by swelling
- Body area affected
- Has the swelling been present for more than three months?
- Does the swelling disappear over night?
- Does the swelling relate to previous cancer treatment?
- Is the patient being treated for leg ulceration?
- Is the patient receiving treatment for lymphoedema/chronic swelling?
- What type of treatment does the patient receive and where?

Mapping the current service

- Healthcare professional's contact details
- Number of patients with chronic oedema/lymphoedema seen in the past year
- Services to which patients have been referred for the treatment of chronic oedema/lymphoedema in the past year
- Treatments provided by the healthcare professional themselves for lymphoedema/chronic oedema
- Treatment and services available to people with chronic oedema/lymphoedema in the local area
- From where would the healthcare professional seek information on treatment for lymphoedema/chronic oedema?
- Difficulties encountered in treating patients with chronic oedema/lymphoedema
- Information required on the management of chronic oedema/lymphoedema

*One form should be completed for each patient.

EUROPEAN HEALTH POLICY AND LYMPHOEDEMA

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Opportunities for the development of lymphoedema services are arising as part of the wider process of change occurring in European health services. Healthcare funders throughout Europe are seeking greater integration of care and to manage patients in more effective ways through longer term care programmes. Lymphoedema presents a rewarding area for developing new services and for improving quality of life.

used. This relatively straightforward process is readily applicable to different models of healthcare, including insurance-based models. By highlighting gaps in current service provision and identifying the levels of specialist and generalist care required, this process will provide the data to drive service planning.

Whatever approach is used, however, the true extent of lymphoedema/chronic oedema is difficult to determine accurately. For example, current epidemiology is thought to underestimate the number of patients affected by at least one-third³.

Ineffective resource usage

An effective case for a service will also show how current resources are being used ineffectively and how clinical and cost-effectiveness outcomes will be improved (see Keeley and Franks, 2007¹⁰). For example, it is clear that many patients with lymphoedema/chronic oedema are not known to a lymphoedema service. However, a process of patient identification (see pages 3 and 4) will show that many patients are already known to other healthcare services, where they probably receive inappropriate care at high resource usage.

DEFINING THE DESIRED SERVICE

Producing a realistic projection of a new lymphoedema service, how it will function and what it will require will involve consideration of a wide range of factors (Box 5), not least the model of care to be adopted.

There is currently, in the UK at least, considerable interest in the Kaiser Permanente model of care for chronic conditions⁷, which describes the relationship between level of required intervention and condition severity (Figure 2) (see www.natpact.nhs.uk). This model

has several features relevant to the development of integrated primary care-based lymphoedema services, including:

- minimising the use of acute hospital beds
- focusing strongly on the management of chronic diseases
- breaking down barriers between primary and secondary care
- emphasising community care, eg intermediate care, home care and self care¹¹.

The Lymphoedema Framework Project's international consensus document *Best Practice for the Management of Lymphoedema* has defined criteria for different levels of intervention according to the stage, severity and complexity of lymphoedema⁸. These criteria can be related to the Kaiser Permanente triangle:

Level 1 Supported self care (self-care support/management)

The Kaiser Permanente triangle suggests that up to 80% of all people with long-term conditions (such as lymphoedema/chronic oedema) could be managed using supported self care. Although a lower percentage of patients seen in many lymphoedema services will be managed in this way because services are unlikely to see all those affected, the figure of 80% should be seen as a target. Patients suitable for this level of care may also be seen in many other parts of the healthcare system and therefore widespread availability of appropriate information and patient education is vital. In addition, research has shown that a strategy for improving knowledge and practice amongst healthcare professionals is essential¹².

Level 2 Long-term management (disease-specific care/management)

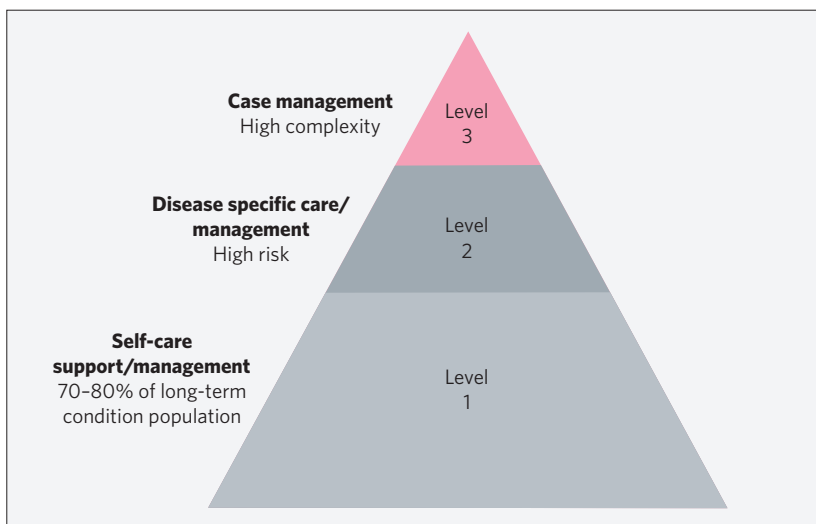
This involves providing people with lymphoedema/chronic oedema with responsive multiprofessional care delivered within an integrated service that uses the recommendations of *Best Practice for the Management of Lymphoedema*⁸. This will include a network of appropriately trained community-based practitioners who are supervised by a specialist lymphoedema practitioner.

Level 3 Intensive treatment (high complexity case management)

This includes the provision of intensive therapy for complex patients and the supervision of shared care programmes of health and social care to meet the needs of these patients. This level of intervention includes all patients requiring intensive therapy programmes as set out in *Best Practice for the Management of*

FIGURE 2 Kaiser Permanente triangle⁷

A healthcare model for chronic conditions that relates condition severity to level of intervention required.



BOX 5 Factors to consider when planning a service (adapted from¹³)**The size of the problem**

Consider how to establish the size of the problem. It will be necessary to determine prevalence, provider of care and place of treatment. The true scale of the problem may not be immediately apparent, with patients being managed in a number of clinical areas

Support and resources

It is essential that the service is well supported and resourced by management. Managers will require evidence derived from the literature or audit to support proposed improvements in practice

Model of care

Consider the model of care to be used for the service. Link the care provided to self care, long-term management and intensive therapy programmes

Multidisciplinary involvement

How will the relevant disciplines be involved in the new service? What will the referral pathways look like?

Integration

Consider how acute and community services will be integrated to provide the most effective service for patients

Coordination

Consider how the service will be managed, coordinated and monitored

Marketing and communications

Consider how to promote the service. How will other healthcare professionals know the service exists, what it has to offer and how to make appropriate referrals to it?

Research-based protocols

The service should deliver care firmly grounded in best practice as identified in *Best Practice for the Management of Lymphoedema*⁸ and take account of the latest research as it is made available

Roles and training

Specialist and generalist roles should be identified and a comprehensive and ongoing training programme should be developed that reflects the needs of all practitioners

Accessibility

The service should be flexible in its organisation and allow easy access for patients seeking treatment

Risk assessment

A risk assessment, in line with current regulations, of all premises and equipment likely to be used will be necessary

Transport

A cost-effective, reliable transport system will be required if patients are to be brought to clinics

Sustainability¹⁴

What factors will be important in guaranteeing sustainability of the service?

Evaluation

Regular evaluation will be required to ensure standards are maintained and health outcomes met

*Lymphoedema*⁸. Patients who are stabilised as a result of this level of intervention may then enter level 2 (long-term management).

MAKING THE CASE

A written proposal, business plan or funding application is invariably essential for securing funding. Its purpose is to provide funding agencies with a concise overview of the proposed service and attendant costs. It is critical that any proposal is in a format acceptable to the intended funding agency. Many agencies will have templates for applications and individuals from whom advice can be obtained. Wherever possible a dialogue with the agency should be established early in the proposal development process.

The case should be realistic and grounded in local need. It should clearly indicate service outcomes and their relevance to current national health priorities. It should also detail how the service will be introduced, how it will integrate with existing services and the likely effect on reducing hospital admissions. Services should be based on the international standards of practice

set out in *Best Practice for the Management of Lymphoedema*⁸ (see editorial, page 1).

One of the pressures on existing lymphoedema services internationally has been a failure of funding agencies to understand different care packages. Attempts have been made to reduce funding for intensive therapy in the misplaced belief that this is saving resources. Consequently, the proposal must clearly define the different care packages, the rationale for their use and the associated costs. Box 6 outlines a possible service proposal document structure.

CONCLUSION

Despite the difficult financial climate affecting healthcare worldwide, it is possible to influence the development of lymphoedema services by preparing and presenting a case that is feasible and has clear benefits. It is unrealistic to expect clinicians to tackle this complex issue on their own and a process of consultation and partnership is essential. Once funding is secured, the challenge is then to develop an effective implementation plan to make the service a reality.

BOX 6 Outline service proposal document structure

The outline provided here is a suggestion for the structure of a service proposal document. However, if available, the requirements of individual funding agencies should be identified and followed.

Title of proposal

Name(s), position(s), qualifications, current role(s), contact details of applicant(s)

Summary

Short summary of the proposed lymphoedema service, including its rationale, costs, and benefits, eg to patients and in meeting national guidance

The need for the service

What is lymphoedema and how does it affect patients? Consider use of clinical photographs

How lymphoedema is managed, treatment benefits, response rates

The size of the problem (prevalence)

Current service provision

The proposal

Model of care, anticipated benefits and contribution to current health initiatives

Objectives of the service, with timescales, considering:

- Area to be served
- Patient profile: adults/children, aetiology/stage/anatomical site of lymphoedema, referral sources
- Staffing, skill mix (generalist/specialist/administrative), training/education
- Development of a patient register
- Level of care (number of clinics)
- Standards of care
- Treatment protocols
- Management of patient recall
- Integration of acute and community services
- Multidisciplinary involvement and referral pathways
- Accessibility and transport
- Work environment (premises/clinic space)
- Equipment
- Patient education and skill development (including expert patient programme), support/user groups
- Monitoring patient satisfaction

Evaluation

- Service monitoring strategy (methods to capture data for evaluation)
- Service monitoring group (with patient representation)

Costs

Costs for each phase of development (recruitment, staff salaries, training, premises, equipment, professional insurance, administrative costs)

Costs of treatment packages, eg intensive therapy

Is the application for the first year or the total cost? Are other sources of funding being sought?

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Setting up and developing a lymphoedema service

T Hill¹, R Davies²

Establishing and developing a new lymphoedema service may be a daunting prospect. However, the potential for improving patients' lives is considerable. This paper will support healthcare professionals in the decisions they need to make when devising action plans and strategies for dealing with the practicalities of setting up, running and developing a lymphoedema service. Experience gained from the development of the community-based Enfield Macmillan Lymphoedema Service in the UK (Box 1) underpins much of this paper. However, many of the principles described also apply to new or expanded services being developed outside the UK and under different funding arrangements.

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Once funding of a new lymphoedema service or its expansion has been confirmed, a phase of intensive and detailed planning will be necessary (Figure 1). The objectives presented in the funding proposal (see Morgan and Moffatt, 2007¹) should be broken down into distinct phases and actions. Where feasible, instigating the most readily achievable objectives first will allow service development to gain momentum. Objectives phrased to be specific, measurable, agreed, realistic and time limited (SMART) are most likely to be attained². Planning should

ensure service sustainability (see *NHS Sustainability Model and Guide*³).

The timescales involved in service development will be highly individual and dependent on a multitude of factors, especially funding and staff availability. Box 2 outlines a possible time frame for service development and suggests broad objectives that may be appropriate.

Deadlines can be powerful motivators, but it is essential to avoid being overambitious. It is likely that at least several months will be required after

BOX 1 Case study – Enfield Macmillan Lymphoedema Service

The Borough of Enfield is located 12 miles north of central London and has a population of about 287,500^{4,5}. Epidemiological studies⁶ suggest that Enfield has approximately 600 patients with chronic oedema. At present, the service has 480 patients.

The Enfield lymphoedema service began in 1992 with preliminary funding from the Queen's Nursing Institute^{7,8}. The charity Macmillan Cancer Support provided interim funding for a full-time clinical nurse specialist. Enfield Primary Care Trust took full funding responsibility from 1998. In 2005, the Enfield service joined the Lymphoedema Framework Project in its work to develop primary care-based lymphoedema services.

The considerable increase in referrals in recent years is partly due to efforts to raise awareness of the service and to educate healthcare professionals. Patients are now generally referred at earlier stages of the disease, reducing the need for intensive therapy, increasing patient satisfaction and quality of life, and reducing hospital admissions for cellulitis.

	1997	2007
Caseload	130 adults (1 child)	473 adults (7 children)
New patients in previous 12 months	78	216
Aetiology (cancer:non-cancer)	80:20	50:50
Clinics	<ul style="list-style-type: none"> Three nurse-led clinics weekly (12 hours/week) in one location 261 appointments/year 	<ul style="list-style-type: none"> Nine nurse-led clinics weekly (36 hours/week) in four different locations 1303 appointments/year
Home visits	<ul style="list-style-type: none"> 6 hours/week 32 appointments/year 	<ul style="list-style-type: none"> 25 hours/week 592 appointments/year
Staff	<ul style="list-style-type: none"> One specialist lymphoedema practitioner (30 hours/week) 	<ul style="list-style-type: none"> Two specialist lymphoedema practitioners (67.5 hours/week) One lymphoedema practitioner (22.5 hours/week) Two link workers (8 hours/month) One administrator (15 hours/week)

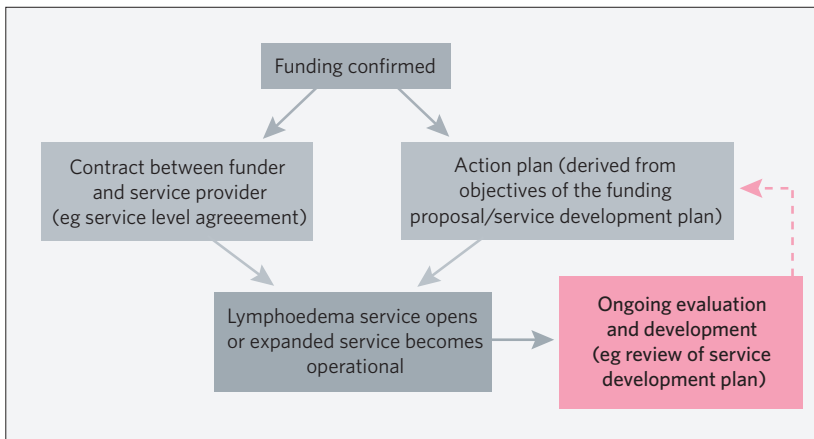


FIGURE 1 Overview of lymphoedema service set up and development

confirmation of funding before the first patient can be seen. Opening the service in a staged fashion will help to maintain control of the workload.

MODEL OF CARE

A multitude of factors will influence the optimal model of care for a particular population. In the UK, the government’s emphasis on community-based care, the increasing average age of the population and the long-term, often debilitating, nature of lymphoedema, indicate that local

primary care-based management best meets the needs of most people with lymphoedema⁹.

A carefully set up service should provide an easily accessible, multiprofessional service that improves equity of access, promotes early intervention (including for patients at risk of lymphoedema), limits disease progression, reduces the need for time-consuming intensive therapy, and lowers hospital admission rates for cellulitis.

AREA TO BE SERVED AND PATIENT PROFILE

The service proposal will define the geographical area to be covered, the type of patient who will be seen (ie adults and/or children, aetiology/ stage/anatomical sites of lymphoedema) and from where referrals will be accepted. Gradual implementation of the service may aid initial management of referral numbers. Providing referral sources with a service-specific referral proforma (Box 3, page 10) will encourage appropriate and sufficiently detailed referrals.

STAFFING

The type and level of clinical staffing that can be funded will be the main determinant of treatment

BOX 2 Outline objectives for setting up a lymphoedema service

Each service will need to develop its own timescale and objectives. Those outlined here are intended as suggestions only.

Prior to service opening

- Recruit a specialist lymphoedema practitioner to lead the service
- Open the service within x months of funding confirmation
- Secure clinic space for x sessions per week
- Source equipment required
- Develop plan to raise service awareness amongst healthcare professionals and the public
- Visit other lymphoedema clinics for advice and support
- Produce referral, assessment, treatment and onward referral protocols
- Build relationships with other healthcare professionals, eg with referral sources and onward referral points
- Develop systems for dealing with referrals, booking appointments, contacting patients and feeding back to referral source
- Secure an administrative base and support

Year 1*

- Recruit x lymphoedema practitioners
- Open x additional clinic sessions
- Provide home visits
- Deliver awareness and clinical training on lymphoedema/chronic oedema to community nurses and other healthcare professionals

Year 2*

- Recruit and train x link workers
- Open additional clinic sessions at x different sites

Year 3*

- Set up a patient support group
- Raise awareness of ‘at risk’ groups

Long-term objectives (Years 5-10)*

- Expand to provide sufficient clinics to see all patients in the community with lymphoedema
- Secure further funding as appropriate

*Evaluation and audit are essential ongoing objectives.

BOX 3 Information for inclusion on a referral form

- Patient's name, date of birth, sex, address, telephone number, patient number
- Patient location – eg home or hospital ward
- Referrer's and primary care physician's name and contact details
- Urgency of referral (urgent/routine); requirement for domiciliary visit
- Reason for referral
- Diagnosis and relevant investigations
- Current treatment
- Medical, psychosocial, family and drug histories, allergies, mobility
- For patients with cancer: site of cancer, history of surgery, lymph node biopsy or clearance, radiotherapy, chemotherapy
- Where to return form

offered and number of patients treated. Training generalist staff will increase service capacity, allowing the clinical specialist to concentrate on leading the service and treating complex patients.

Clinical staff***Lymphoedema practitioners***

The practitioner leading the service should be trained in lymphoedema to specialist level¹⁰. Additional training in business skills and personnel management may be necessary. Lone practitioners should take action to avoid becoming overwhelmed as caseload increases, and should set aside time for planning, professional development and networking.

It is essential for all practitioners to develop a professional support system. Support may be gained from immediate colleagues, regular meetings with managers, meetings organised by professional groups, clinical supervision, annual appraisal and continued involvement of the team who developed the initial service proposal.

All practitioners will need to maintain and develop their knowledge and practical skills by attending appropriate training courses, clinical meetings and conferences, and observing others' practice. Practitioners should ensure that training courses undertaken are accredited by recognised educational organisations. In some instances, educational bodies run courses in careful partnership with lymphoedema-related businesses.

Community nurses

Much of the workload of community nurses involves supporting patients with long-term conditions in their own homes. With appropriate training, community nurses can support the work of a community-based lymphoedema service by:

- identifying those with or at risk of developing lymphoedema
- referring patients as appropriate to the lymphoedema service

- planning, implementing and evaluating skin care
- recognising cellulitis and initiating treatment within guidelines
- undertaking simple spiral multi-layer bandaging
- working collaboratively with the lymphoedema service and intermediate care teams to allow palliative care/housebound patients to receive lymphoedema bandaging at home.

Box 4 describes how community nurses were encouraged to become involved in the Enfield Macmillan Lymphoedema Service.

Link workers

Link workers are an essential component of an integrated lymphoedema service¹¹. They work with the lymphoedema service to provide care for patients with mild, uncomplicated lymphoedema who are in the long-term management phase, and act as a referral point and source of advice for other community nurses (Box 5).

Administrative support

Administrative support is invaluable in reducing clinical staff workload, improving service efficiency and ultimately speeding service development. If funding for dedicated administrative support is not available, it may be possible to share administrative staff with other services or to use volunteers for carefully selected tasks.

DEVELOPING RELATIONSHIPS WITH OTHER HEALTHCARE PROFESSIONALS

The diverse aetiology, chronic nature and wide spectrum of effects of lymphoedema contribute to the need for close links with a broad range of health and social care professionals, groups and services (Figure 2 and Box 6). Building such links will improve the quality of direct referral, increase awareness, raise the profile of the service and bring greater understanding of each other's

BOX 4 Developing community nurses – The Enfield Experience

- Sessions were run for community nurses during lunchtimes to raise awareness of the Enfield service and provide an overview of lymphoedema and its management
- Three areas were identified and developed to provide a rolling programme of teaching sessions for community nurses:
 - skin care in lymphoedema
 - cellulitis
 - lymphoedema bandaging
- Involvement in management (under the guidance of a specialist lymphoedema practitioner) has allowed community nurses to learn new skills, saved specialist time in caring for housebound patients, and encouraged some nurses to become a link worker
- The inclusion of compression hosiery on the UK Drug Tariff has prompted a review of training needs with a view to eventual involvement of appropriately qualified community nurses in the provision of compression garments

BOX 5 Tips for success with link workers – The Enfield Experience

- Identify community nurses who wish to take on a link worker role
- Negotiate with managers to set up a contract that allocates and protects time for the link worker role
- Facilitate participation in a suitable link worker course, ensuring time is allocated for practical experience and to ensure competency
- Following completion of the course, assign the link worker to manage a follow up clinic, ensuring regular support
- Ensure that members of the lymphoedema service and local community nursing teams are aware that this link worker is available for referral and advice
- Ensure that the link worker has easy access to more experienced practitioners and has regular opportunities to observe practice and develop their skills, and is encouraged to extend their role as appropriate

capabilities¹². Enhanced awareness of other services will enable lymphoedema practitioners to ensure that their own referrals are appropriate. If medical expertise or specialist investigations (eg lymphoscintigraphy, CT/MRI, ultrasound) are not available locally, it may be necessary to refer patients with primary or complex lymphoedema to a regional centre. Close links with hospital consultants will facilitate admission where necessary for patients with cellulitis.

The recently widened access to compression garments in the UK through the *Drug Tariff* and the *Nurse Prescribers' Formulary* increases the importance of links with pharmacists.

TREATMENT TO BE OFFERED

The number of clinic sessions/home visits and treatment offered will depend on the stage, aetiology and anatomical location of the lymphoedema to be managed and the availability and skills of staff (Box 7, page 12). In general, clinical contact time should take up approximately two-thirds of a member of staff's time.

The development of treatment, investigation and onward referral protocols will promote good practice and staff development. The

Lymphoedema Framework Project's international consensus document *Best Practice for the Management of Lymphoedema* provides standards of practice and clear treatment guidelines that form a solid basis for the development of protocols⁹.

Managing clinics

Especially in the early days, there will probably be considerable pressure on practitioners' time, with more patients to be seen than appointments available. It is useful to remember that many patients will have had swelling for a long time and that their problems will not be resolved in one visit.

Where a service runs clinics in several locations, planning should allow time for travelling between sites and ensure that each clinic has the necessary equipment and resources.

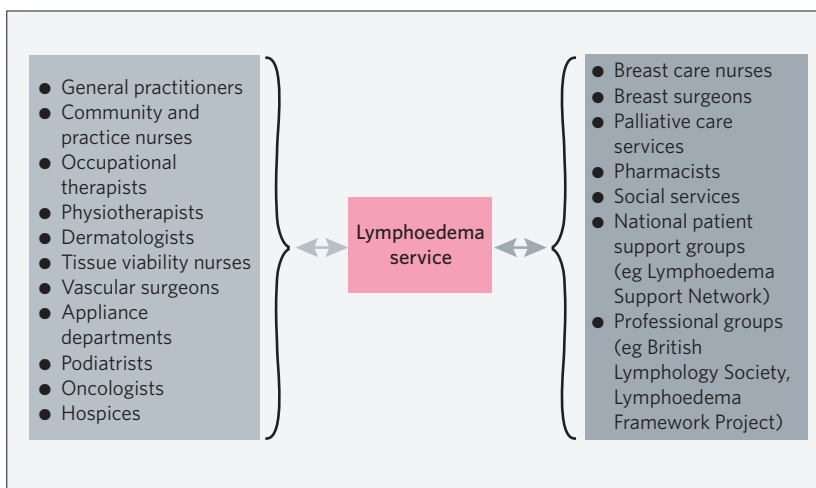
If a patient is admitted to hospital, whether as a result of lymphoedema or not, it is vital to liaise with hospital staff to ensure that any ongoing treatment is continued or modified as appropriate, and that the lymphoedema service is informed when the patient is discharged. It may be appropriate to visit the hospital and to support staff in the delivery of lymphoedema-related care.

It may be helpful to develop a series of proformas for recording assessment and treatment, communicating with the referral source/primary care physician, and requesting onward referrals.

Managing home visits

Home visits can be extremely time consuming, especially if the service covers a large geographical area. Careful planning to group appointments according to patient location and to avoid travel during rush hour, as well as

FIGURE 2 Links between lymphoedema services and other health/social care professionals, services and groups



BOX 6 Tips for developing multidisciplinary relationships

- Plan time for developing professional relationships
- Contact potential referrers with a description of the lymphoedema service and referral criteria
- Invite other healthcare professionals and managers to spend time with the lymphoedema service
- Encourage lymphoedema practitioners to visit other services
- Arrange meetings with other clinical specialists
- Offer to speak at meetings – eg protected learning times and conferences
- Participate in health service open days – eg by exhibiting
- Form links with health service patient user groups

BOX 7 Tips on running clinics

- **Avoid overbooking clinics and allow time for writing up notes**
- **Consider how to minimise cancellations/non-attendance**
- **Confirm patients' appointments in writing, including details of what the appointment is for, where it will be, when and for how long, who they will see, parking/transport arrangements and what to do if they are unable to attend or have any questions**
- **Consider appropriate appointment length - eg in Enfield:**
 - **initial assessment (including providing advice and appropriate educational materials) - one hour**
 - **multi-layer lymphoedema bandaging (MLLB) - 30 minutes**
 - **MLLB plus manual lymphatic drainage - 90 minutes**
 - **follow up (including limb measurement, checking compression garment, advice on skin care, simple lymphatic drainage and psychological support) - 30-60 minutes**
- **Will each clinic consist of appointments of the same or different types, ie will some be for assessment or follow up alone?**
- **Allow extra time for appointments or leave gaps in the schedule in the early days of the service and for new members of staff**
- **Develop contingency plans for staff holidays and sickness**

judicious use of locally available link workers or community nurses, will save time.

When visits are made to patients in residential and nursing homes it is important to involve carers and nurses to enable them to take on care. Such visits can also provide educational opportunities as many other residents may be at risk of or have lymphoedema.

WORK ENVIRONMENT AND EQUIPMENT

Locating clinic and office space for the service may require imaginative solutions. Although dedicated facilities are ideal, initially, a new lymphoedema service may need to use existing clinic facilities, eg in health centres, community

hospitals or hospices. Service development may include opening clinics in several locations across the area to be served.

The chosen location should have disability access, public transport links and readily available parking. The location may bring additional benefits to patients, speeding referrals and saving time. For example, it may be possible to use or acquire clinic space in a facility alongside tissue viability and podiatry services and near a pharmacist. Treating patients with cancer-related lymphoedema in a hospice may provide access to complementary therapies, counselling and advice on state benefits.

Some clinic rooms may already be equipped with basic furniture and equipment, but it is inevitable that some purchases will be necessary (Box 8). Storage space will also be required.

Working in patients' homes

Working in patients' homes requires the practitioner to be highly adaptable in their implementation of treatment. Care must be taken to avoid commencing treatments that may compromise patient or practitioner safety when administered in a home environment. Requirements for manual handling of patients must be considered and advice from experts in this field should be sought as appropriate.

PATIENT EDUCATION AND SUPPORT/USER GROUPS

Education enhances the partnership between the patient and practitioner that is essential for successful treatment of lymphoedema and promotion of self care. Literature that can be taken home will help patients to retain information provided.

BOX 8 Equipment that may be required**Clinical equipment**

- **Adjustable clinical couch**
- **Linen and couch rolls**
- **Limb measuring tapes**
- **Method for calculating limb volume (specialist calculator/computer program)**
- **Compression garment measuring equipment (tapes/measuring boards)**
- **Doppler equipment and sphygmomanometer**
- **Camera**
- **Skin care supplies, including dressings**
- **Bandaging/foam/padding/tape**
- **Compression garments**
- **Patient support wedges**
- **Wheeled stool**

Other equipment

- **Telephone, answering machine, fax machine**
- **Computer, printer, stationery**
- **Desk, chair, lockable filing cabinet**
- **Chairs for patient and visitors**
- **Panic button in areas known to have problems with crime**

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

BOX 9 Tips for setting up a patient support group

- Ask patients what they would like
- Advertise the meetings; consider sending individual invitations
- Plan a programme of topics for discussion
- Consider inviting external speakers
- Aim to meet regularly, but not too frequently
- Consider varying the venue and meeting time to maximise attendance
- Plan to step back from running the group and encourage members of the group to take on leadership and planning

Practitioners may choose to develop their own patient education programmes and literature, or to make use of those available from national lymphoedema or cancer support organisations, eg Lymphoedema Support Network or Cancerbacup. Information should include whom to contact if problems develop.

The development of a patient support group will help patients to feel less isolated and provides opportunities for learning about lymphoedema (Box 9). The group can act as a forum for patients to express their needs and to make suggestions. National patient support groups may be able to assist the set up of local support groups.

RAISING AWARENESS OF 'AT RISK' GROUPS

Secondary lymphoedema has a wide range of causes and may not become apparent until months or years after the causative event. By identifying patients at risk of lymphoedema and educating them and healthcare professionals about the condition, it is hoped that condition severity can be limited through early referral and intervention. Potential targets for raising awareness of lymphoedema risk include healthcare professionals who treat breast, gynaecological or urological cancers. Attending multidisciplinary meetings, offering literature and training on the aetiology, prevention and treatment of lymphoedema, and working with units to devise and deliver tailored patient education can raise awareness.

EVALUATION

Evaluation will be essential for providing evidence for continued service funding. Importantly, it will also be central to ongoing service development and delivery of a high quality, patient-centred service¹³.

It is advisable to ascertain from funders what evaluation criteria will be required and to put into place systems to collect the necessary data as the service is being set up (see Keeley and

Franks, 2007¹³ for more information on evaluation of lymphoedema services).

CONCLUSION

Lymphoedema service development is challenging and potentially hugely rewarding. Services should be designed and developed individually to meet local needs. Careful planning and the development of close professional relationships with all members of multidisciplinary teams are essential. The service should be evaluated regularly alongside review of the service development plan.

AUSTRALIAN LYMPHOEDEMA SERVICES

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In Australia, in common with many countries, the seriousness of lymphoedema is largely unacknowledged and government funding of lymphoedema services is inadequate.

In metropolitan Australia, services are found mainly in the private sector and range from solo practitioners to larger multidisciplinary clinics. Clinics are often overloaded and unable to provide optimal time for treatment and education. Provision of affordable compression garments and services to those without private health insurance is a major issue.

Outside metropolitan areas, patients often travel large distances for treatment. In most services, time for lymphoedema is restricted by the plethora of other issues that patients present. Services are significantly underfunded and their nature is dependent on staff experience and expertise.

Regional services often consist of two to four staff, and rural/remote services generally consist of highly committed solo practitioners. Patients with significant lymphoedema and associated morbidities are often referred to larger centres. Patients and their partners are often forced to undertake self-treatment (usually under some instruction) when specific services are unavailable.

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Roles in lymphoedema services

MC Sneddon

Lymphoedema services vary widely across the UK. Differences and inequities are evident in the level of service provision geographically and for certain types of lymphoedema. However, inequity also extends to the type, number, roles and level of expertise of the healthcare professionals involved. This paper reviews the issues relating to roles in lymphoedema services that have become apparent over recent years in the UK. It considers the implications of recent developments in the UK National Health Service (NHS) and the critical role of the patient. In the light of experience and current socio-political drivers, proposed key roles and capabilities of future practitioners in lymphoedema are presented. These aim to ensure that lymphoedema services are effective and continue to develop to meet changing needs. Although independent privately-funded lymphoedema practitioners play a role in care provision, their contribution is not addressed within this paper.

Of the four European configurations of lymphoedema service provision identified by MacLaren¹, hospital or hospice-based outpatient provision, often focused on cancer patients, has been most prevalent in the UK. More recently, a need to locate services in the community has been identified² and is supported by current governmental drivers³.

The main professional groups involved in lymphoedema services are physiotherapists, nurses and occupational therapists, with some more predominant than others in different locations. Some services have several staff with a high level of skill (uni- or multiprofessional); others rely on a single professional who treats lymphoedema as part of a wider role, and who may have limited training or experience.

Most services in the UK are practitioner led. This differs from some European models, eg in Austria and Germany, which tend to be medically led and delivered by trained therapists from specialist centres of excellence¹.

INFLUENTIAL MODELS OF SERVICE DELIVERY

Two models of service delivery influence current lymphoedema service provision in the UK. The British Lymphology Society (BLS) model⁴ was derived from a model of care developed by Badger⁵ and was moulded by two documents that examine the needs of patients and an educational framework^{6,7}. Both documents are currently under review. The more recent Lymphoedema Framework Project (LFP) model supports a system of primary care-based, specialist-led care that involves patients, families, carers and generalist practitioners⁸.

Significantly, both models recognise that the level of care required by patients with complex disease should be differentiated from that required by patients who are at risk of lymphoedema or who have less complex disease. Therefore, for specialists to focus on complex cases, other practitioners are needed to undertake standard

long-term management of those with stable lymphoedema and to manage those with early or less complicated forms of the disease. Such practitioners (who may be known as key workers or link workers) have a vital role in minimising disease progression.

Both models emphasise the role that **all** healthcare practitioners play in recognising patients at risk of developing lymphoedema and in informing such individuals of the risks, preventative strategies and what to do if a problem arises.

Attempts have been made to apply the BLS model in a 'hub and spoke' fashion with the specialist at the hub and the key workers providing a more limited, often part-time service in the community or more distant centres. Frequently, where provision cuts across care sectors, there has been a lack of coordination at health authority/board level and of differentiation between specialist and key worker roles. As a result, regardless of level of training or competency, all levels of practitioner have been seeing all complexities of patient, perhaps compromising the quality of treatment.

The LFP model is being piloted in various primary care trusts in England and is guided by the recommendations of *Best Practice for the Management of Lymphoedema*⁹. The results of the pilot scheme evaluations are awaited with interest and appear to be encouraging.

SPECIALIST AND HIGHER LEVEL ROLES

The management of lymphoedema has been defined as a specialism because it requires a complexity of knowledge and skills beyond that of generalist practitioners¹⁰. However, it is important to differentiate an individual who has developed skills in a specialised area of practice from an individual who is a specialist. The first may have developed skills to treat very complex lymphoedema to a high standard, but may not function as a specialist in the broader sense. This involves acting as an agent for

change and leading practice developments with a high degree of autonomy¹¹.

In reality, many practitioners with specialist skills have been thrust into service development and management, sometimes with little preparation or support. Clearly, it is not appropriate for all such clinical experts to take on these roles, and they may not wish to do so. However, to move forward, lymphoedema does need leaders who take on strategic and political roles.

THE CHANGING NHS

In the UK, Agenda for Change reforms arose from the NHS Plan to improve services and develop a more skilled, flexible workforce¹². As part of the reform, the NHS Knowledge and Skills Framework (NHS KSF) was developed^{13,14}. This competency-based framework defines the knowledge and skills required at various levels of working across the NHS, and also influences pay.

The Skills for Health Career Framework (CF), which interfaces with the NHS KSF, differentiates nine levels of responsibility (Table 1) and suggests appropriate levels of education for each¹⁵.

Both frameworks are intended to support professional development and address capability in addition to competence. It has been suggested that emphasising capability (the ability of individuals to apply knowledge and learning from experience to enhance their performance) improves the ability of practitioners to develop in ways that meet the ever-changing demands of healthcare provision^{16,17}.

The NHS KSF and Skills for Health CF will be of considerable importance in the UK. They offer opportunities for practitioners to identify professional development and educational needs and to progress their careers. It is vital that practitioners have a sound understanding of both frameworks and can clearly demonstrate what they do and what they need to enable them to deliver more extensive or complex services.

TABLE 1 Key elements of the Skills for Health Career Framework¹⁵

The Skills for Health Career Framework is an evolving system that was derived from Agenda for Change and aims to aid implementation of a flexible career and skills structure within the UK NHS.

Career Framework level	Description
1	Initial entry level jobs
2	Support workers
3	Senior healthcare assistants/technicians
4	Assistant practitioners/associate practitioners
5	Practitioners
6	Senior practitioners/specialist practitioners
7	Advanced practitioners
8	Consultant practitioners
9	More senior staff

PROPOSED ROLES

Application of the NHS KSF and the Skills for Health CF may help to discern roles within lymphoedema services because they will require that each post has detailed outlines describing the level of skill and decision-making involved.

Aligning existing roles within lymphoedema services with the Skills for Health CF will not prevent variations in the way roles are perceived within any particular level or grading. However, adopting consistent terminology across all lymphoedema services may help other professionals to appreciate the various roles, and may help to identify clearer pathways for progression and development of competencies.

When determining the level of the roles it will be important to recognise that practitioners in the UK specialising in lymphoedema may be qualified to prescribe and that their role may require them to make clinical decisions more commonly associated with the medical profession. As a result, professional development of lymphoedema practitioners will require cultivation of general diagnostic skills to ensure that co-morbidities are identified and that appropriate referrals are made.

Table 2 (page 16) draws on existing lymphoedema service models and the Skills for Health CF to propose role titles and a crude outline of possible role components. These will require debate and consensus.

The role components indicated in Table 2 are specific to lymphoedema. Role profiles developed for employment purposes will also need to reflect the more generic attributes and abilities required, eg promotion of patient empowerment and support of self care and rehabilitation.

Non-professional roles

Throughout the NHS healthcare assistants in nursing, physiotherapy and occupational therapy have become increasingly involved in care delivery. The general roles of such assistants, who are not registered healthcare professionals, are identified in the Skills for Health CF. By developing their skills, often in specific areas, assistants can relieve some of the burden of professionally qualified staff.

Lymphoedema is no exception. Some areas are currently exploring the potential role of the lymphoedema assistant practitioner, who would always work under the direction and supervision of a professionally qualified staff member.

Professional roles

There may be problems in applying the Skills for Health CF to those who manage lymphoedema as part of a more generic role, eg key/link workers or community nurses. These individuals may find that

TABLE 2 Proposed roles for lymphoedema service practitioners

Title	Skills for Health Career Framework (CF) level	Examples of key components specific to lymphoedema	Educational level
Lymphoedema Assistant Practitioner*	4	<ul style="list-style-type: none"> Works at all times under the direction and guidance of a state registered practitioner, probably at CF level 6, who would be responsible for treatment decisions and planning care Undertakes basic assessment, eg measurement of limb volume, and basic treatment, eg skin care, and provision of information on exercise, skin care and care of compression garments Administers simple multi-layer lymphoedema bandaging (MLLB) in conjunction with lymphoedema practitioners 	<ul style="list-style-type: none"> National Vocational Qualification (NVQ) level 3 or equivalent in Assessment of Prior Experiential Learning (APEL) Possibly studying for a Foundation Degree or Higher National Diploma (HND)
Lymphoedema Practitioner*	5	<ul style="list-style-type: none"> Plans care for those with uncomplicated lymphoedema and those with stable lymphoedema in long-term management, including skin care, exercise, simple lymphatic drainage (SLD) and compression garments. Also performs simple bandaging under guidance of a practitioner at CF level 6 or 7 Undertakes assessment, monitoring, patient support and information provision Makes referrals to other disciplines as necessary Acts as a resource for colleagues 	<ul style="list-style-type: none"> State registered practitioner Degree level education and appropriate clinical training in assessment and management of relatively uncomplicated lymphoedema
Lymphoedema Specialist Practitioner*	6	<ul style="list-style-type: none"> Manages all types of lymphoedema with a degree of autonomy and responsibility for own caseload Supports and guides practitioners at CF levels 4 and 5 Developing towards a CF level 7 role 	<ul style="list-style-type: none"> State registered practitioner with degree level education and training as for above plus a lymphoedema management certificate incorporating intensive therapy, manual lymphatic drainage (MLD), MLLB
Lymphoedema Advanced Practitioner	7	<ul style="list-style-type: none"> Experienced clinical professional empowered to make high level clinical decisions and who has high standards of clinical skills (including assessment and diagnosis of lymphoedema and other conditions) and theoretical knowledge Manages and leads developments within own service while retaining a key clinical and educational role Supports and acts as a resource for lymphoedema practitioners and lymphoedema specialist practitioners (CF levels 5 and 6) 	<ul style="list-style-type: none"> State registered practitioner with a degree level course in lymphoedema management Holds or is working towards a master's degree Training in comprehensive clinical examination skills
Lymphoedema Consultant Practitioner	8	<ul style="list-style-type: none"> High level strategic role in developing and managing services, perhaps for a health board/authority In addition to being a clinical expert, undertakes research. Perhaps working towards leading and coordinating research or supporting others in research activities Involved in education, teaching at a high level, perhaps with honorary university appointment to support research activity Clinical commitment would be condensed and focus on complex cases and offering support to other clinical team members 	<ul style="list-style-type: none"> State registered practitioner with appropriate clinical training as above Holds a master's degree; possibly working towards a doctorate

*These roles may be undertaken on a part-time basis as part of a more generic role.

each role equates to a different Skills for Health CF level, eg their main remit may fit CF level 5, but their contribution in terms of lymphoedema might equate to CF level 6. They may also find it difficult to gain recognition of the higher level aspect of the role in their NHS KSF banding, which may act as a disincentive to taking it on. However, the reverse may also be true and individuals may be advantaged by taking on additional roles. The Skills for Health website (see www.skillsforhealth.org.uk) is currently developing a database of roles mapped with the NHS KSF for guidance.

The Skills for Health CF also identifies a role at level 9. However, it is unclear what such a post involves, and none exists at present.

The NHS KSF and the Skills for Health CF do not apply to medical roles. However, where available, the involvement in lymphoedema services of knowledgeable medical practitioners is invaluable, especially in the diagnosis and management of cases with complex congenital abnormalities or co-existing disease processes.

CHANGING CARE PRIORITIES

The major changes underway in the NHS include changes in the way people are cared for by professionals. Recognition of the growing numbers of people in the population living with long-term conditions has necessitated a different approach to the provision of care and support. The Department of Health proposes a three-part model of care³:

- supported self care
- specialist care for those with complex needs
- a case management approach for those with highly complex or multiple needs.

There are clearly some parallels with the existing approaches to lymphoedema management.

Other aims for chronic disease management relevant to lymphoedema include anticipating and detecting problems early, minimising the effects of the condition and reducing complications, and promoting independence and empowerment. Moreover, the intention is to provide care that is planned, proactive and seamless to avoid crises and to "give patients the most intensive care in the

LYMPHOEDEMA SERVICES IN THE NETHERLANDS

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In ambulatory settings in the Netherlands, skin therapists and physiotherapists specialising in lymphoedema treat patients referred by a doctor. The treatment provided is reimburseable, and circular and flat knit compression garments can be prescribed and funded for RAL-GZ classes II-IV. Admission to hospital is most commonly for complications such as cellulitis/erysipelas.

Nij Smellinghe Hospital in Drachten has a specialist lymphology department for complex diagnostics, and non-surgical and surgical treatment of lymphoedema. The multidisciplinary team comprises dermatologists, surgeons, skin therapists, physiotherapists, urologists, rehabilitation specialists, specialist nurses, psychosocial workers and dieticians. The hospital has agreements with insurance companies until 2007 for funding additional to the standard reimbursement system.

Dutch national guidelines for lymphoedema that provide evidence-based guidance and expert opinion on diagnostics, multidisciplinary treatment and follow up were published in 2003 (see www.lymfoedeem.nl).

least intensive setting", ie to move away from an acute care setting focus³.

Patient role: supported self-care

Various government documents support the need to increase the involvement of patients with long-term conditions such as lymphoedema in their treatment and in developing services. They stress the need for a "radical shift in the balance of power, with the patient at the centre"^{3,18}.

Recommendations include developing strategies to enable people to have the best possible quality of life and to develop the ability to assess and monitor their own condition, to know when to seek help, and to adopt means that aid recovery and deal with their condition¹⁸. The provision of information and development of skills that enhance patients' confidence will be essential.

Impact on healthcare professionals

The philosophy underpinning the proposed NHS changes affects how newer roles develop and where services are located. It may also aid funding applications for more lymphoedema education and the appointment of more practitioners at key/link worker level, ie at proposed lymphoedema practitioner CF level 5 role.

Although not formally recognised as such, lymphoedema is a long-term condition that cannot be cured. A major focus of the key/link worker role is to provide information, advice, education and support that enables people with lymphoedema to take responsibility for managing their condition so that they may live as normal a life as possible^{6,9}.

Minimising the extent of professional input may be seen as a cost-saving exercise. However, equipping individuals with the necessary understanding and skills, and fostering adequate

confidence to undertake so much self care, requires considerable investment of time and effort. It may also require practitioners to develop sophisticated skills in patient education, support and empowerment, including enabling, motivating, facilitating and teaching skills, and to employ a partnership approach. Such abilities and qualities are not innate, and unfortunately the need to learn and develop these skills is often overlooked.

CONCLUSION

This paper provides an opportunity to consider existing models of lymphoedema service provision and to achieve consistency of terminology with the frameworks arising from NHS reforms. New role titles need to be considered and related clearly to tasks and corresponding levels of knowledge and skills. It should be possible to ensure that defined roles are easily identifiable within the Skills for Health CF and that individuals holding these roles have the knowledge and skills they need.

In identifying the way forward, the governmental focus on patient driven services, empowerment and support will also require consideration. It is likely that the 'shape' and approach of services will need adaptation and some practitioners may need to further develop generic skills that will enhance patients' self care.

It is recommended that practitioners engage in a review of roles and terminology, and examine their own roles in light of the NHS KSF and the Skills for Health CF. There is great potential for practitioners to use these frameworks to advance their own development and career progression whilst simultaneously enhancing the service provided to people with, or at risk of, lymphoedema.

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Evaluating a lymphoedema service

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The evaluation of healthcare services is becoming increasingly important worldwide as demand and expectations rise and more pressure is placed on available resources. Evaluation aims to ensure that clinical services meet the needs of the catchment population, ensure equity of access, meet agreed standards of practice, achieve successful outcomes, meet national guidance and targets, and are financially effective. This paper explores these areas in relation to lymphoedema service evaluation.

In the UK, several national processes for evaluation have been developed and many healthcare services are assessed regularly against a series of preset standards or quality measures¹ (see www.healthcarecommission.org.uk; www.nhshealthquality.org; www.hiw.org.uk). At present, however, the assessment of lymphoedema services is not included in detail in these processes. In a step towards addressing this gap, the Lymphoedema Framework Project (LFP) has developed standards of practice against which lymphoedema services can be assessed².

Funders of lymphoedema services are likely to require evaluation data before ongoing investment is guaranteed. Even if not specifically required, evaluation should be considered 'good practice' and may identify scope for service development. Determining evaluation criteria and developing processes for capturing the required data should be integral to initial service planning.

When evaluating lymphoedema services for a given health community, it is important to assess individual components, eg the central specialist service and the peripheral generalist service, as well as the combined service so that gaps in overall provision are identified.

It is recommended that the format of any evaluation report is agreed with funders. However, in the absence of guidance, the areas covered in this paper could form the framework of a report:

- meeting needs and ensuring equity of access
- standards of practice
- clinical outcomes
- patient satisfaction
- health economics.

MEETING NEEDS/ENSURING EQUITY OF ACCESS

A description of the lymphoedema service and who can access it forms the basis of evaluation (Box 1). Data should be recorded annually to demonstrate trends and performance against any contract with healthcare commissioners.

An estimation of the number of patients in the catchment area likely to need treatment for lymphoedema can be derived from published figures^{3,4}. This figure can be used to provide an indication of service coverage, ie the proportion of affected patients who are actually being treated.

Equity of access can also be assessed using simple measures, eg number of referrals accepted

BOX 1 Descriptors for evaluation of meeting needs and ensuring equity of access

- Catchment area – eg geographical area, population demographics
- Types of chronic oedema treated – eg primary/secondary lymphoedema, cancer-related, lymphovenous and other chronic oedemas
- Types of patient seen – eg adults, children
- Referral sources and pathways
- Staffing – eg practitioners, doctors, administrators
- Access to other services – eg vascular surgery, investigations
- Transport, parking, access for disabled patients
- Treatments available – eg intensive therapy, manual/simple lymphatic drainage (MLD/SLD), intermittent pneumatic compression (IPC)
- Activity – eg clinic frequency, numbers of home visits, new patients, follow-ups, intensive treatments given, patients treated and discharged, waiting times to first appointment and for treatment after assessment
- Staff training/professional development; education/training provided for other healthcare professionals
- Patient support group – eg availability, activity

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BOX 2 Clinical outcome measures

- Reduction in swelling – eg limb volume measurement
- Changes in skin and subcutaneous tissues
- Range of movement of affected limb
- Incidence of cellulitis
- Quality of life measures
- Measures of comorbidity or general health

or refused, ease of access by wheelchair users and types of chronic oedema treated (Box 1).

Other aspects, such as equity of gender or ethnicity, are more difficult to measure because figures do not exist for the ‘norm’ of each in a given population with chronic oedema. Some measure of geographical equity can be obtained by comparing referrals by postcode with estimates of prevalence.

STANDARDS OF PRACTICE

It is recommended that services are assessed in relation to the standards of practice for lymphoedema services published by the LFP^{2,5} (see editorial, page 1). This will identify gaps in provision that can be addressed by future service developments.

Given the current state of development of lymphoedema services in the UK, many of the detailed elements of these standards are likely to be aspirational. Furthermore, at present, there is no published audit tool that can be used to measure compliance with the standards.

CLINICAL OUTCOMES

There are no national or international standards for expected clinical outcomes of lymphoedema treatment. The LFP’s document *Best Practice for the Management of Lymphoedema* does, however, provide a basis for standardising the assessment and treatment of lymphoedema⁵. Auditing adherence to the document’s guidance can provide a measure of the quality of service provision and of compliance with the LFP’s standards of practice. Clinical audits of patients’ response to treatment are also recommended (Box 2).

Some outcome measures, eg photographs, may be useful in managing individual patients, but are not easy to collate and analyse for a report on a group of patients. Other outcomes, eg limb volume measurements, are more readily quantifiable and can be used to describe treatment outcomes for groups of patients or for a whole service.

Reduction in swelling

Most healthcare professionals use limb volume measurements to monitor outcome⁶. These may be derived from tape measurements or the use of an opto-electronic device, eg Perometer.

In patients with unilateral limb swelling, the percentage excess volume of the swollen limb in comparison with the unaffected limb is frequently used. It could be argued that a fully successful treatment reduces the percentage excess volume to zero (allowing for the normal slight asymmetry of limbs, where the dominant limb is usually larger). However, despite adequate treatment, this may not be achievable, eg due to fibrosis or tissue

thickening and fatty tissue proliferation in patients with long-standing lymphoedema.

In most cases of bilateral limb oedema, it is not possible to establish a volume that would represent a reduction to normal. However, in patients at risk of lymphoedema secondary to surgery, preoperative measurements could be used to establish a target volume.

It is widely accepted that limb volume measurements alone do not accurately reflect the outcome of treatment. Patients often report satisfactory improvement when tissues feel softer and skin condition or limb function improves, even if limb volume has not changed particularly.

Volume in midline structures, eg head and neck, trunk and genitalia, is not easy to measure and the objective evaluation of the response to treatment in these areas is difficult.

Changes in skin and subcutaneous tissues

There are several ways of assessing skin and subcutaneous tissues changes due to treatment (Box 3). However, none is accepted as standard.

Range of movement of affected limb

Currently, there is no standardised way of describing improvement in limb function/movement that is easily applicable to measuring treatment outcome in groups of patients. Possible approaches include the use of goniometry (measurement of range of movement using angles), quality of life tools that include function as a specific domain (see below), and the non-condition specific WHO disability assessment scale (see www.who.int/cidh/whodas).

Incidence of cellulitis

It has been shown that combined physical treatment of lymphoedema resulting in the reduction of limb volume reduces the incidence of cellulitis⁷. It is, therefore, suggested that the incidence of cellulitis and any resulting hospital admissions are recorded. A reduction in admissions will reflect potential savings of healthcare resources.

Quality of life measures

There is currently no published condition-specific quality of life (QOL) tool for all types of lymphoedema¹³. However, more general QOL tools, eg EuroQol¹⁴ and SF-36¹⁵, have been used and condition-specific tools are in development, eg LYMQOL¹⁶. These tools assess different domains, eg symptoms, function, mood, and appearance/body image, to build an overall QOL measure. The tools can be used to estimate the impact of chronic oedema on QOL at the time of presentation and to demonstrate changes due to treatment.

BOX 3 Outcome measures for changes in skin and subcutaneous tissues

- **International Society of Lymphology (ISL) staging system⁷** – can be used to define stage at presentation, but may be too insensitive to measure changes resulting from treatment (Box 4, page 20)
- **Multifrequency bioimpedance analysis (MFBIA)** – can detect changes in extracellular fluid volume and so can be used to assess response to treatment⁸. Indeed, for unilateral arm oedema, it may be more sensitive than conventional limb volume measurement⁹. However, its use in bilateral lymphoedema is not yet fully established⁸
- **Tonometry** – assesses tissue thickening and fibrosis in a more objective way than does palpation¹⁰. However, the exact place of tonometry in practice has yet to be established. It may have a role in assessing truncal oedema
- **Ultrasound measurement of skin thickness** – can aid diagnosis of lymphoedema¹¹. However, its role in evaluating treatment response is not clear

Measurement of comorbidity

Patients with chronic oedema often have significant comorbidity that may affect QOL, mobility and response to treatment. Although there is no validated tool for the measurement of comorbidity, a QOL tool may help to assess the effect of treatment in patients with lymphoedema and some types of comorbidity. For example, in a patient with chronic lymphovenous oedema as a result of a neurological condition, treatment may not improve domains directly related to the comorbidity, eg mobility. However, a reduction of swelling may improve other QOL domains, eg symptoms, mood and body image.

Anxiety and depression can be measured specifically with the Hospital Anxiety and Depression Scale (HADS)¹⁷.

Comparing clinical outcomes between services

There are a number of potential difficulties in comparing clinical outcomes between different services. A generalist service that treats patients with mild uncomplicated oedema is likely to have better outcomes than a specialist service that treats patients with complicated oedema and significant comorbidities. It is, therefore, important to attempt to 'compare like with like'.

One approach may be to define condition severity in the population treated. However, even though staging oedema at presentation using the ISL system (Box 4) may be helpful, it is not likely to be sensitive enough to predict clinical outcome accurately and does not take into account comorbidities.

Another approach that allows for a basic comparison between services is to categorise patients according to the BLS classification of patient groups¹⁸, which divides patients into four groups: those at risk; those with mild and uncomplicated oedema; those with moderate to severe or complicated oedema; and those with oedema and advanced malignancy.

PATIENT SATISFACTION SURVEYS

Patient satisfaction surveys, eg the Patient Centreometer¹⁹, are often used to obtain users' views of services. Many are designed by healthcare providers themselves and examine:

- access – eg disabled access, car parking
- waiting times – eg for assessment, at clinic
- information given – eg written, verbal
- staff communication/behaviour
- facilities – eg cleanliness, décor
- potential service improvements.

It may be possible to adapt existing questionnaires to produce a survey specific to a lymphoedema service. However, as these questionnaires are not

specifically validated for lymphoedema, results should be interpreted with care.

HEALTH ECONOMICS

In an ideal world, the only measure of service success would be whether patients' health was maximised by use of the most effective treatment. However, limited financial resources force politicians, healthcare managers and the wider population to set priorities.

Health economic analyses evaluate the outcomes of treatment in relation to the costs involved and so can be used to identify care that is most efficient, ie that provides the greatest benefit to the most patients according to the finite resources available.

Costs

Defining the full cost of lymphoedema for formal health economic analysis requires an assessment of the direct costs to healthcare services, the financial costs to patients, and the costs to society of a patient having to take time off or give up work, or dying early (Box 5).

Formal health economic analyses

Two of the most widely used formal health economic analyses are discussed below.

Cost-effectiveness analysis

Cost-effectiveness (CE) analyses are most commonly used for pharmaceutical interventions, and calculate the cost of producing a defined clinical outcome, eg cost per myocardial infarction prevented. Without consensus on the key clinical outcome variable for the treatment of lymphoedema it is hard to justify CE analysis for this condition.

Cost-utility analysis

Cost-utility (CU) analysis does not use defined clinical outcomes. Instead, the outcome used represents a single score of health that is derived from a combination of the duration of life and an index of health state (quality of life).

Scores derived from tools that examine health state, eg EuroQol¹⁴, can be expressed as a range of values including death (zero) and 1.0 (perfect health) that are known as utilities. The use of utilities relies on the assumption that years of perfect health can be traded for longer periods of poorer health, eg one year of perfect health (utility = 1.0) is considered equivalent to two years of health with a utility of 0.5.

As a result, utilities derived at different stages in a patient's life (or disease) may be multiplied by years of life within each state to derive a single

BOX 4 International Society of Lymphology staging system⁷

ISL stage 0

A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident

ISL stage I

This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage

ISL stage II

Limb elevation alone rarely reduces swelling and pitting is manifest

ISL late stage II

There may or may not be pitting as tissue fibrosis is more evident

ISL stage III

The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop

BOX 5 Examples of potential costs of lymphoedema

Direct costs to the healthcare service

- Organising and operating costs within the health sector – eg administrative costs, building maintenance, heating and lighting
- Professionals’ time – eg time spent treating patients
- Supplies – eg compression bandages, dressings, compression garments
- Equipment – eg diagnostic and therapeutic equipment
- Capital costs – eg computers

Direct costs to patients

- Expenses – eg cost of attending hospital/clinic
- Patient and family input into treatment – eg cost of prescriptions, privately funded care

Indirect costs/costs to society (lost production caused by ill health)

- Taking time off work
- Changing jobs – eg moving to a lower paid, or part-time job
- Giving up work – eg requiring alternative source of income, ie pension or state support
- Lost production caused by early death

BOX 6 Guide to estimating direct healthcare costs

Direct healthcare costs could be estimated from:

- number and type of investigations
- clinic/home visits
 - number of visits
 - average time spent with patient per visit
 - healthcare professional seen
 - disposables used (eg bandages, dressings and hosiery)
 - travel time (for home visits)
- hospitalisation related to lymphoedema or its consequences, eg cellulitis
 - number of inpatient days
 - specialty caring for patient

index incorporating *quality* and *quantity* of life – the quality adjusted life year (QALY). So four years with a utility of 0.5 would be equivalent to two QALYs. CU analysis calculates a financial cost per QALY.

QALYs produce a single outcome measure that allows for comparisons between different medical interventions for the same disease and also between diseases. As QALYs do not rely on a particular clinical outcome measure, they may be valuable in conditions like lymphoedema.

Health economics in practice

Performance of CE and CU analyses requires a degree of understanding of health economics, and healthcare professionals involved in lymphoedema services should usually concentrate on direct healthcare costs (Box 6).

Liaison with hospital finance departments may provide valuable information on the costs of

individual resources. Alternatively, national figures are available for many key items used in the NHS²⁰.

UK NATIONAL DRIVERS

In the absence of UK national guidelines for lymphoedema service development or evaluation, the guidance on lymphoedema services for cancer patients included in the National Institute for Health and Clinical Excellence (NICE) document *Improving Supportive and Palliative Care for Adults with Cancer*²¹ should be taken into consideration. In addition, lymphoedema services need to take into account current national drivers to increase community-based care²² and Department of Health targets such as the maximum 18-week wait for treatment²³.

Although governmental drivers can force health service commissioners to fund lymphoedema services, it is likely that the patient voice will become ever more influential in shaping government agenda. The Lymphoedema Support Network (LSN) has had success in lobbying the UK government and is actively targeting NHS Primary Care Trusts to develop services for patients with lymphoedema.

CONCLUSION

Although in the UK there is, as yet, no nationally agreed process for evaluating lymphoedema services, there are a number of existing methods of assessing their effectiveness. In the absence of a national programme, service providers should build evaluation into service planning and development and should consider assessing their own services using the methods described.

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