



INTERNATIONAL
LYMPHOEDEMA
FRAMEWORK

**Focus
Document**

A photograph of several smooth, dark grey stepping stones arranged in a line across a shallow body of water. The water is clear and blue, reflecting the sky and the stones. The background is a soft, out-of-focus landscape with hills under a bright sky.

Lymphoedema Frameworks – The Way Forward

www.lympho.org

Belong  Together

The logo consists of two stylized human figures, one blue and one orange, with their arms raised and hands meeting in the center, forming a heart-like shape.

Introduction

THE INTERNATIONAL LYMPHOEDEMA FRAMEWORK

The International Lymphoedema Framework (ILF) was established as a charity in the UK in 2009. Its aim is to improve the management of lymphoedema and related disorders worldwide, by sharing expertise and resources and supporting individual countries to develop a long term strategy for lymphoedema. Such a strategy will:

- **Raise the profile of lymphoedema** nationally and internationally
- Place lymphoedema and its management **as a priority on national health care agendas**
- **Enable clinicians to lobby for appropriate financing or reimbursement** of lymphoedema care
- Address issues of **inequity of provision**
- **Implement and evaluate lymphoedema services** based on best practice
- **Create an international lymphoedema community** that collectively strives to improve the evidence base for treatment and professional practice
- **Improve the lives of lymphoedema sufferers worldwide.**

Introduction

The work of the ILF builds on the UK Lymphoedema Framework established in 2002. **The UK project involved a partnership** with expert clinicians and researchers, lymphoedema organisations, patient support groups and industry and **developed a national research project involving the implementation of an internationally agreed standard of best practice within different service models.** This led to the adoption of a new classification of lymphoedema through the UK drug tariff, allowing access through prescription to all products required for treatment.

A global minimum data set

An international minimum data set for the evaluation of health outcomes is being developed by ILF and will be used for all participating countries.

International Advisory Board

An International Advisory Board is responsible for providing advice and expertise to support the work of the ILF. The board comprises international experts of renown in the field of lymphoedema and academic/clinical leads of participating countries. Members of the board are drawn from developing and developed countries.

Effective partnerships

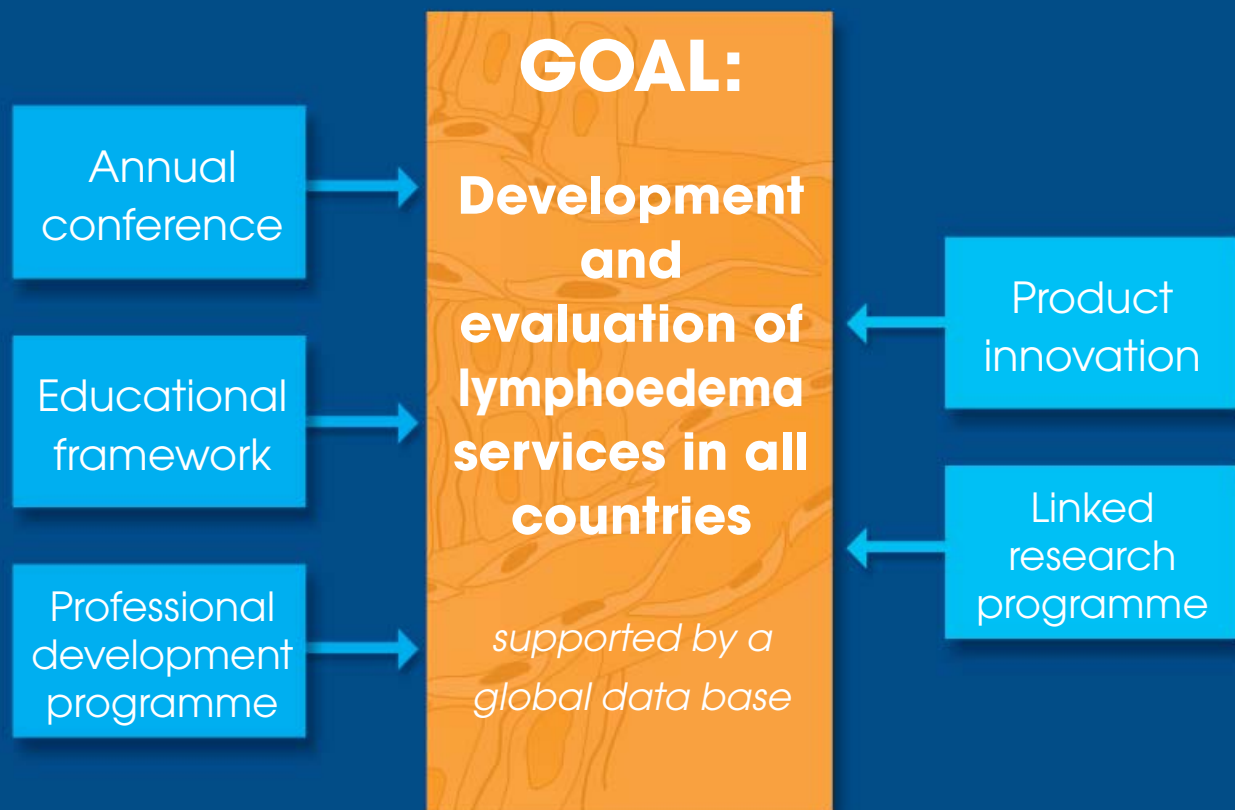
Effective partnerships are being established with key agencies and organisations involved in lymphoedema worldwide. These include:

- World Health Organization (WHO) and World Alliance for Wound and Lymphoedema Care (WAWLC)
- Global Alliance for the Elimination of Lymphatic Filariasis (GAELF)
- International and national lymphology groups
- Patient support groups

Introduction

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PARTNERSHIP APPROACH



Introduction

Key aspects of the ILF

There are a number of aspects of the ILF to which participating countries are asked to contribute. These are set out as follows.

Annual International Conference

A major vehicle for the ILF is an annual international conference. Conferences, which will be held in different countries, are highly interactive involving participation of all delegates, including industry partners and patients and their advocates.

The conference gives an opportunity for working groups and expert panels to meet. Of particular importance is the dialogue between western and eastern approaches to lymphoedema care and problem solving of global issues such as eradication of infection. A patient conference is also hosted during each conference.

Educational and Professional Development Initiatives

The ILF aims to establish a comprehensive educational framework. This will include international recommendations on curricula and the development of educational materials for use throughout the world. The need for a professional development programme is also a priority.

Innovation

As the field of lymphoedema develops, opportunities for product innovation will emerge. Partnerships with the industry members will foster this work and should lead to new approaches to diagnosis and treatment. Such innovation will be the subject of rigorous research.

We believe the management of lymphoedema should be improved in all countries around the world and that the methodology recommended by the ILF to set up and implement National Lymphoedema Frameworks, is the way forward.

National Lymphoedema Frameworks

ILF METHODOLOGY - A 10 STEP PROCESS

1. Recognition of the need to improve the management of lymphoedema by one or more stakeholders. This recognition can be triggered by any or all of the following:

- Epidemiology studies
- Poor or no recognition of lymphoedema by health care systems
- Flaws, disparities or inequities in the provision of care
- Absence of appropriate management for some or all patients.

2. Creation of the core team of individuals willing to tackle the issues and ready to give some of their time and energy.

3. Identification of all the stakeholders in the management of lymphoedema nationally and description of the current management.

4. Strengthening of the core team with representatives of all stakeholders to ensure the necessary multi-disciplinary approach to the project.

5. Foundation meeting(s) to clarify the vision and the aims but also the structure of the NLF (legal status, leadership, representation, etc).

6. Stakeholders' Open Space Meeting to identify all issues/barriers in the current management of lymphoedema and to identify possible solutions/synergies.

7. Definition of roadmap by the leaders of the NLF:

- Priorities and agenda
- Working groups
- Definition of the necessary adaptations to the ILF Best Practice for the Management of Lymphoedema document
- Definition and deadlines of deliverables.

8. Management of project and definition of a fair and cost-efficient management of lymphoedema adapted to the national health care system.

9. Delivery of a strategy to improve lymphoedema management in the country.

10. Measurement of outcomes using an international minimum data set and programme of continuous research and development.

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WHILE EACH NATIONAL LYMPHOEDEMA FRAMEWORK (NLF) IS UNIQUE, THE FOLLOWING STAGES ARE NECESSARY TO HELP ENSURE SUCCESS

- ▶ Identify academic/clinical leads.
- ▶ Identify stakeholders.
- ▶ Identify the executive committee.
- ▶ Incorporate the executive and stakeholders into a steering group.
- ▶ Arrange steering group meetings to decide:
 - The structure of the NLF
 - Roles and responsibilities
 - Definition of the aims
 - Scope of work
 - Timelines
 - Funding strategies
- ▶ Plan a stakeholders' open space meeting (see over). This can be facilitated by ILF and gives an opportunity for all stakeholders to contribute. This will enable the executive committee to:
 - Identify all issues that will have to be addressed
 - Identify possible solutions
 - Involve all current stakeholders
 - Identify any additional key stakeholders
- ▶ The open space event culminates in a report that informs the strategic plan for the NLF and identifies the working groups that are required to implement this.
- ▶ Undertake a scoping exercise that defines current practice and indicates where developments are required in order to be able to implement best practice.

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- ▶ Adapt as necessary the International Best Practice for the Management of Lymphoedema document for the country.
- ▶ Define appropriate models of care.
- ▶ Define strategy for using the ILF minimum data set as the evaluation tool.
- ▶ Work with reimbursement agencies to ensure that all required data will be included in the minimum data set.
- ▶ Implement best practice within services using the minimum data set to measure health outcomes and cost effectiveness.
- ▶ Use the outcomes from this work to drive improvements in practice and improved reimbursement if required.

“**Open Space Technology** has been defined as the most effective process for organizations and communities to identify crucial issues, give voice to their passions and concerns, learn from each other, and, when appropriate, take collective responsibility for finding solutions.”

(source: www.chriscorrigan.com)

In other words, an Open Space meeting is a participative meeting during which all stakeholders are given the opportunity to express their voice, to work together with other stakeholders, and to play an active role in the process of improving the management of lymphoedema.

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FREQUENTLY ASKED QUESTIONS

What is a National Framework?

It is a partnership of stakeholders within a given country, who are dedicated to improving lymphoedema care.

These include:

- Practitioners
- Researchers
- Patients and patients' advocates
- Related organisations
- Industry

Ideally, a National Framework is a not-for-profit organisation as this embraces the overall ethos of the ILF.

What structure is needed to support a Framework?

- Academic/clinical leads of national and international standing who are able to envision and lead the project
- An executive committee responsible for the daily management of the project
- A steering group of key stakeholders who have the motivation and capacity to drive change
- Working groups who will undertake specific areas of responsibility

How does a National Framework interrelate with the ILF and other NLFs?

The national framework can be supported by the ILF team through any of the following:

- Membership/attendance of the steering group
- Running events
- Help with designing funding strategies
- Provision of tools such as the minimum data set

In turn, the national framework will be asked to:

- Maintain the spirit and ethos of the ILF

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- Participate fully in all aspects of the ILF including conferences and publications
- Deliver an annual report to the ILF on its activities
- Contribute data to the minimum data set
- Contribute to the lymphoedema market data reports

The National Framework will also be asked to agree to a Code of Practice for the sharing of knowledge to support the setting up and work of other NLFs.

What should be the objective of a National Framework?

The objective of an NLF should be to improve the management of lymphoedema in its country by developing a strategic plan that will incorporate:

- Assessment of current care provision and its deficits
- Identification of problems of access and payment of care
- Involvement of stakeholders in strategic planning
- Adaptation of the International Best Practice for the Management of Lymphoedema document as necessary for national requirements
- Definition of appropriate models of care
- Implementation of best practice and evaluation of care using the ILF minimum data set

How important is it to follow the ILF ‘10 Step Process’ methodology?

For many reasons, and especially the different approaches to health care in each country, it is not possible to adopt wholesale what has been done in one country for use in another. Each NLF will therefore be unique. There are however, many common issues and problems and the ILF methodology has been developed to address these.

How is a National Framework funded?

As previously mentioned, a not-for-profit approach is recommended in line with the ethos of ILF.

- **Industry** is usually the most obvious initial source of funding and a sponsoring package for interested

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companies will need to be drawn up with the help of the ILF team.

One of the challenges in obtaining industry support will be to convince companies of the benefits of such a project and more importantly, of its capacity to deliver. Involving Industry as a key stakeholder is usually perceived as added value because it enables them to understand the potential for market development and expansion, which can result from a strategy to improve the management of lymphoedema in a country.

In many countries there are ethical rules about working effectively with industry. The ILF supports the need to ensure that these are adhered to.

- **State funding**, particularly for research aspects of the work, is to be encouraged. Accessing this type of funding is usually linked with the ability to show the long term capacity of the NLF to define a model of care that will contribute to reducing the cost of treatment while providing better care. State funding is however highly competitive.
- **Charitable funding** has been an invaluable source of support in some frameworks and should be actively considered.
- **Self funding** National frameworks should, in time, be able to generate income from their own activities, such as conferences, education programmes and other resources.

What role does industry play?

In the spirit of a national framework, industry should be considered as a key stakeholder and acknowledged as bringing expertise to the project. Along with patients and practitioners, industry will be asked to make an active contribution to the different working groups and potentially to join the steering group, although in a non-voting capacity.

By such involvement industry will be able to:

- Develop a vision for lymphoedema
- Understand the needs of patients and practitioners
- Develop new and better solutions
- Prepare for future market developments.

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Ethical considerations to working with industry

- Each NLF will have the freedom to decide on the role of industry in its projects in line with the ethos of the ILF.
- The executive committee will be responsible for ensuring that the ethical working practices of industry participation are not infringed.
- Inviting industry members to join the steering group does not mean the NLF will be controlled by industry or that larger sponsors will be able to influence product use.
- The presence of industry on the steering group avoids speculation since, as with other members, their input will be recorded in the minutes of the meetings.

What role do patients play?

Patients play a fundamental role in the development of a framework and may be the initiating force. They alone understand what it is like to live with lymphoedema. One of the aims of the ILF is to develop the concept of the expert patient who can, in addition to understanding their own condition, influence the development of lymphoedema care. In the UK, patients within the Lymphoedema Support Network have been actively engaged in all aspects of the work, from strategically driving the project, through to informing reimbursement requirements for the national drug tariff.

How does a National Framework work with existing national and international organisations?

One of the aims of the ILF is to bring together the lymphoedema community at both national and international levels. Within in each country it is essential that existing organisations work together to improve care. A framework does not replace organisations but acts to create an opportunity to work together to drive change. Far from replacing organisations, frameworks should contribute to making them stronger by raising the profile of the condition.

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Is there really a need for a Framework in my country?

An NLF is needed in any country where it is considered that the access to and standard of care requires improvement. Sadly this is the case in most countries.

How long does a Framework last?

A Framework should be considered as a process of continuous improvement rather than a project with a defined end.

What is different about a Lymphoedema Framework?

There are a number of aspects that differ from other approaches:

- The ILF and NLFs are based on a philosophy of partnership between the different groups involved in lymphoedema care.
- Patients play a role in all levels of a framework.
- All stakeholders are considered as experts.
- The international dimension is aimed at promoting and facilitating collaboration and synergy.
- NLFs celebrate national individuality while encouraging support from the international community.
- The ILF believe that it is only through the demonstration of improved health outcomes that lymphoedema will become a health priority recognised and appropriately reimbursed.
- The ILF and all NLFs will seek to contribute to the development of a robust evidence base for lymphoedema care.
- The ILF recognises that lymphoedema is a global health problem that must bring together developed and developing countries through its programmes.

National Lymphoedema Frameworks

10 Tips for a Successful Framework

- Keep focused on the vision
- Concentrate on what matters
- Understand national issues
- Ensure strong leadership
- Maintain good communication
- Ensure vision is supported by action
- Accept collective responsibility for finding solutions
- Encourage motivated skill mix
- Try to avoid inter-professional conflict that prevents progress
- Avoid politics where possible



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The ILF Objective :

To improve the management of lymphoedema and related disorders worldwide

- To increase **awareness** by raising the profile of lymphoedema.
- To increase **knowledge** about lymphoedema by initiating and/or contributing to **Research Programmes**.
- To **disseminate** this knowledge by implementing an **international, not-for-profit, publications strategy**.
- To increase **understanding** of lymphoedema and its management by creating and/or contributing to the development of **Education Programmes**.
- To provide a cross cultural networking platform through an **Annual International Event** where all stakeholders will have the opportunity to contribute and influence the ILF agenda.
- To promote and document Best Practice with the development of an **International Minimum Dataset**.
- To facilitate and/or contribute to better **access to treatment** for patients worldwide.
- To promote and **support initiatives** whose goals are to improve the national/regional/local management of lymphoedema anywhere in the world.
- To help the Healthcare Industry understand the **real needs** of patients and practitioners, and develop and evaluate improved diagnostic tools and treatments.

