

A FRAMEWORK FOR GLOBAL COLLABORATION AND BEST PRACTICE

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It is well recognised that international collaboration is essential if lymphoedema of all causes and in all its various presentations is to be recognised, treated, managed and indeed prevented effectively. A quick look through each issue of this journal since its launch in 2006, shows this to be a consistent message. In the area of prevention, important work has been done by organisations such as the World Health Organization (WHO) and the Global Alliance for the Elimination of Lymphatic Filariasis (GAELF) in terms of filarial vector control (Ryan, 2006). Equally, the prevention of lymphoedema following cancer and its treatment through changes to surgical and radiotherapy practice is a continuing key research focus (Piller, 2006). In addition, many individual researchers across the world have laboured to improve the early recognition, diagnosis, measurement and clinical management of lymphoedema (Piller, 2006; Addiss, 2007).

Despite the numbers of people suffering worldwide, estimated by WHO to be 100 million of all causes and age groups (Ryan, 2007), lymphoedema remains a complex and often misunderstood condition. This complexity is embedded at a number of levels that differs from country to country and manifests itself as a series of challenges, e.g:

- ▶▶ Overcoming problems of reimbursement and identifying the affordability of treatment and who pays for it
- ▶▶ Describing the local prevalence of lymphoedema
- ▶▶ Clarifying and enabling access to specialist management

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- ▶▶ Overcoming local mythology about causation
- ▶▶ Facing the problems caused by illiteracy and ignorance
- ▶▶ Improving levels of general awareness of the condition
- ▶▶ Educating patients as well as practitioners about lymphoedema
- ▶▶ Introducing standards of care and best practice
- ▶▶ Establishing a system of patient support groups
- ▶▶ Exploring the true cost of lymphoedema to the individual and the healthcare system
- ▶▶ Tackling the challenge of poverty alleviation and introducing programmes of low cost self-help
- ▶▶ Improving the availability of and/or access to materials and compression garments
- ▶▶ Integrating traditional therapies with biomedical practice
- ▶▶ Understanding the effect of lymphoedema on both health-related quality of life and the psychosocial health of patients and their families.

This is not a comprehensive list, but, to improve the day-to-day experience of patients there is a clear need to increase our collective understanding of these fundamental issues of lymphoedema morbidity management, which are faced by lymphoedema practitioners across the world, and to tackle them. Arguably, ultimate success is most likely to be achieved within a setting guided by a consensus of best practice and supported by international collaboration. The International Lymphoedema Framework (ILF) offers an approach by which this might be achieved.

The International Lymphoedema Framework Background

The ILF builds on the Lymphoedema

Framework established in the UK over the last five years and which has successfully implemented an internationally agreed standard of best practice within different service models across the UK. This is a project built on collaboration and consensus with expert clinicians, researchers, healthcare organisations, patient support networks and the compression industry. Crucially, the UK project has led to the adoption of a new classification of lymphoedema by the Department of Health Drug Tariff allowing access, through prescription, to all products required for treatment. The project uses a common research dataset which provides a comprehensive evaluation of the size and complexity of the healthcare problem and the clinical, psychosocial and economic benefits of adopting best practice. Early results show considerable improvements in health outcomes across all measures, including the elimination of hospital admissions for cellulitis and significant improvement in the cost-effectiveness of the service.

Aim of the International Lymphoedema Framework

The ILF aims to expand on this work by developing and evaluating appropriate healthcare services for patients with all forms of lymphoedema in partner countries throughout the world. As with the UK project, collaboration and consensus is a central tenet to be applied not only with each partner country, but with key groups involved in the field of lymphoedema worldwide, including: WHO, GAELF, international and national lymphology societies and patient support networks. The research methods used in the UK project will be adapted for the international research programme and will involve, through international collaboration, the development of a global electronic dataset for all participating countries.

Participating countries

The guiding principal of the ILF is to engage countries in the development of national frameworks using service models appropriate for each country. It is anticipated that over the next two years this work will begin in France, Portugal, Japan, India and the United States. Each country will be managed by a project manager who will provide guidance and direction when undertaking the research and developing the profile of lymphoedema within the country. Additional support will be available, where needed, to assist with negotiations with relevant reimbursement agencies to ensure that high quality products are available for care. A critical condition of partnership in the ILF is for each country to ensure that the voices of patients are heard and integrated in the development of the national framework.

Inclusiveness is important to the ILF and country membership will be open to all. It is therefore anticipated that countries will proceed at different speeds and will be encouraged to be involved at different levels, according to their ability to develop services and undertake the research evaluation. Critically, membership will permit access to a range of framework materials designed to assist in the full range of activities necessary to a participating country, for example, service development and specialist and generalist lymphoedema practice. These materials include: the *Journal of Lymphoedema*, templates for practice and educational materials.

Of particular concern to the ILF is to encourage participation from developing countries. Every effort will be made to provide resources to support these countries and allow full participation in the annual international conference and to assist in service development.

Key elements of the ILF

There are a number of key elements which are designed to promote participation, collaboration and best practice in the field of lymphoedema. These are set out in *Figure 1*.

The annual international conference is a major communications vehicle for the ILF. The first will be held in Ascot in

April 2009 and then annually by rotation in each participating country. The conference will be highly interactive and will involve participation of all delegates, including industry partners and patients. Equally, the *Journal of Lymphoedema* forms the key communication channel for the ILF and, in time, it is envisaged that the journal will be published in all the main languages.

An accessible framework of education and professional development is crucial to the success of the ILF. In many countries there is a lack of appropriately trained practitioners who have the specialist clinical and organisational skills to develop and evaluate services. Urgent work is needed to address this lack of expertise and the ILF will seek to develop the necessary support programmes. In addition, more advanced programmes will include:

- ▶▶ PhD fellowships
- ▶▶ Post-doctoral research fellowships
- ▶▶ Specialist modules (available as paper-based and electronically).

As with all aspects of the ILF, the educational work will be supported by the international advisory board, as well as expert educationalists to ensure that the programmes of study are clinically and educationally robust.

As the field of lymphoedema develops, opportunities for product innovation will emerge. Partnerships with appropriate industry will foster this work. A key priority is to consider the development of low cost, locally manufactured materials that patients can afford as well as methods of

eliminating infection at a global level. Such is the nature of the ILF that this will undoubtedly involve partnerships with pharmaceutical companies, as well as the exploration of traditional remedies based on eastern approaches to care.

Conclusion

The ILF is an opportunity for all involved in the field of lymphoedema whether they are patients, clinicians, therapists, academics or industry to look at what can be achieved if meaningful collaboration is adopted as a strategy for change. The UK experience provides a tempting glimpse of what is possible. David Addiss gives a reminder of the similarities between 'north and south' despite current differences in standards and approaches to care, and that these similarities should represent an opportunity for productive global collaboration (Addiss, 2006). The ILF recognises these similarities and that all countries have valuable contributions to make in the endeavour of ensuring that the best care and management possible is available for people with lymphoedema, wherever they may be. **JL**

References

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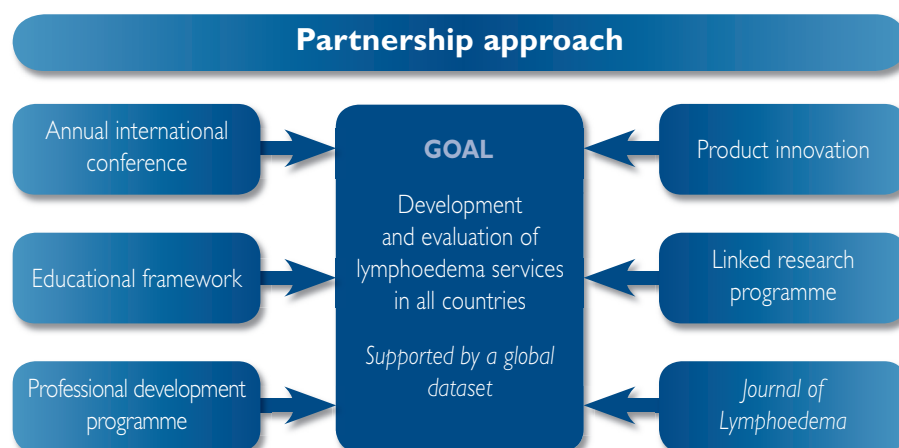


Figure 1. Key elements of the International Lymphoedema Framework.