

# MANAGED CLINICAL NETWORKS: FUTURE FOR LE SERVICE PROVISION

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The Lymphoedema Network Northern Ireland (LNNI) was designed as a managed clinical network to ensure the best use of scarce resources across institutional boundaries. This facilitates work within and between the five regional trusts across Northern Ireland, including sharing of best practice and service improvement projects, working towards a modern, proactive and efficient service. The network's goal is to change the incidence pattern over the next 10 years by improving awareness and prevention practice, and ensuring holistic management of the most complex cases.

## Key words

Managed clinical network  
Efficiency  
Education  
Stakeholder involvement

The Lymphoedema Network Northern Ireland (LNNI), a managed clinical network, was formed in 2008 as a result of the recommendations of the Department of Health, Social Services and Public Safety Northern Ireland (DHSSPSNI) document: *Lymphoedema Services — report of the Lymphoedema Services Review Group* (2004). This report reviewed the paucity of regional clinical access in 2004 and defined the standards and progress to be made to establish a modern and accessible service across the province. The motivation for the proposed outcomes was fully supported by the panel patient representatives, one of whom stated:

*Cancer can be a death sentence, but lymphoedema is a life sentence.*

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The regional plan for the development of a managed clinical network was designed to ensure the best use of scarce specialist expertise, standardise care and improve services building on existing resources, but creating a user-focused and coordinated body, integrated and locally responsive, and, most importantly, unconstrained by existing professional and health boundaries (DHSSPSNI, 2005). This formalised structure also establishes a recognised body of expertise governed by its own constitution, terms of reference and stakeholder membership.

## Key recommendations

Regional progress is focused by the key recommendations of the lymphoedema services review (DHSSPSNI, 2004). These include:

- ▶ Lymphoedema network: a Northern Ireland network of lymphoedema services should be established. Patients with primary and non-cancer related lymphoedema should have equal access to the service. Commissioners and providers should develop an integrated network of lymphoedema services in each board area to provide a high quality standard of care, which is realistic and achievable
- ▶ Specialist lymphoedema services: commissioners and providers, as part of the network, should establish specialist lymphoedema services within the Belfast, northern, southern, western and south eastern trust areas. In addition to specialist lymphoedema clinics, it is recommended that commissioners should work towards the provision of more local services, for example at local hospitals or treatment centres or hospices
- ▶ Trained lymphoedema network: the specialist lymphoedema clinics should be run by a trained network of lymphoedema practitioners, all of whom will have completed an accredited lymphoedema course and had three-yearly updates. They should have good communication links and care pathways with other relevant hospital services, in particular the cancer centre and cancer units and hospices, but also with dermatology, vascular, tissue viability services and primary care
- ▶ Practitioners: the LNNI should have dedicated specialist lymphoedema practitioners, who would work to agreed guidelines and protocols in the specialist lymphoedema clinics
- ▶ Assistants: healthcare assistants should be appointed to the lymphoedema network to help free up lymphoedema practitioners' time from basic administration and more routine duties
- ▶ Consultant medical practitioner: commissioners and providers should ensure that a consultant medical practitioner, working in the specialist lymphoedema clinics, develop a

special interest in the management of patients with lymphoedema.

### Lymphoedema Network Northern Ireland

The network's vision is to change the emerging picture of the condition over the next 5–10 years by initiating an early screening programme, awareness campaign and early clinic access which will be supported by the regional cardiovascular and cancer service frameworks. This would include:

- ▶ The combination of the screening awareness/early access programme and new complex assessment clinics will manage either end of this referring group, slowing down the prevalence rates related to this chronic condition
- ▶ The combination of a new minimum dataset, province mapping review and personal and public involvement (PPI) projects will produce information to support future business plans for Northern Ireland.

A long-term plan would be to begin cross-border collaboration with the health providers from Eire.

The remit of the network is to co-ordinate and shape regional service development to provide a high standard of accessible care throughout the province as recommended by the Clinical Resource Efficiency Support Team (CREST) document: *Guidelines for the Diagnosis, Assessment and Management of Lymphoedema* (2008). This, the network:

- ▶ Acts as a mentor for the five individual trust leads (one per health and social care [HSC] trust)
- ▶ Provides strategic direction (including multiprofessional and cross-sector education, audit, research and patient support)
- ▶ Provides a voice for health promotion, public relations, strategic communications, future commissioning opportunities and potential joint ventures with other agencies outside the public sector.

The network also draws together existing services and supports the vision of a boundary-free region, where support is provided by each trust to the adjacent trusts. This has already

proven beneficial with waiting list management as each of the trust's has developed and recruited at different rates, thus allowing some degree of regional coordinated cover during this initial implementation phase. This will continue to be of benefit as the profile of lymphoedema is raised and the resultant increase in referrals occurs.

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To achieve this goal, the LNNI is actively developing and promoting:

- ▶ The profile of lymphoedema (prevention and management), including lobbying within all care sectors
- ▶ High standards of locally available lymphoedema management for all patients with lymphoedema and those considered to be 'at risk' of developing it
- ▶ Support for the individual trusts in the development of local equitable services across Northern Ireland
- ▶ Lymphoedema prevention/screening for 'at risk' patient groups to increase early diagnosis and immediate service access, promote prevention/patient self-care and knowledge of regional services and ultimately reduce prevalence rates
- ▶ Lymphoedema management: informing and influencing health policy, models of service delivery (in line with the CREST Lymphoedema Guideline, 2008) and education (both uni and multiprofessional at generalist and specialist levels) across all care sectors.

The initial review (DHSSPSNI, 2004) had recommended £1.26 million to implement this project, however only £500,000 was eventually made available for the task. As such, the network management team has had to re-address traditional approaches to service

provision in order to introduce this new modernised model of care.

Key to the implementation has been the designated funding for a 0.4 whole time equivalent part-time project lead (Band 8B [consultant post]) and full-time project manager (Band 7 [experienced project manager with audit and data analysis skills]). This investment has allowed the successful development of clinical and non-clinical associated services. The importance of leadership and project management skills has been highlighted as central to the creation of a successful network. Similarly, access to Department of Health guidance, commissioners, IT designers, audit and research resources has been crucial to progress.

### LNNI board

To complete this role, a regional network board has been formed to govern and guide the actions of the regional team. The LNNI board, through the executive authority of its member organisations, is responsible for the implementation of lymphoedema service policy on an equitable and sustainable basis for the population of Northern Ireland, giving leadership and direction to the work of the network while ensuring that all those with lymphoedema in Northern Ireland have access to high quality person-centred care. The LNNI board, project team and PPI constitutions and terms of reference are all available on the LNNI website ([www.lnni.org](http://www.lnni.org)).

The LNNI board meets quarterly and the constituent members include HSC trusts, HSC boards, stakeholders and DHSSPSNI representation, namely:

- ▶ Chair: AHP officer – Public Health Agency
- ▶ Vice Chair: network clinical lead
- ▶ Clinical Lead
- ▶ Project manager
- ▶ Two commissioners, representatives of the Health and Social Services boards
- ▶ Primary care representative
- ▶ Five patient health and social care trust representatives
- ▶ Five health and social care trust clinical leads.

One representative from the DHSSPSNI observes.

The Chair is accountable to the constituent members of the network for ensuring that the Lymphoedema Network delivers on its responsibilities. Each trust also has a named director/co-director with whom the trust lead links. They, along with the physiotherapy/cancer service managers, also receive copies of all board minutes and relevant paperwork regarding structure and work streams. A quarterly report is for the Department of Health (Northern Ireland) and directed to the Director of Secondary care. The LNNI board discharges its responsibilities through its project team, patient and public involvement forum and local trust networks.

### LNNI work streams

The network has three formal work streams:

- ▶▶ Education
- ▶▶ Communication
- ▶▶ Lobbying and influencing.

Strategies have been developed to support these activities and are available on the website. The key projects forming the baseline work for the network support the strategy goals and the overall aim of the network – to inform on current service provision and provide a means of achieving the network's vision.

### LNNI key projects

#### Regional mapping project

This project was designed to inform the board of the extent of current services, including:

- ▶▶ Availability of adequate resources, including appropriately trained staff, treatment/administration areas, goods and services
- ▶▶ Educational standards and access
- ▶▶ Multidisciplinary support and access to other teams and investigations
- ▶▶ Available funding.

The mapping report is available from the LNNI website (December 2009) and focuses on the goals for service development planning and associated lobbying.

### Formation of a complex assessment clinic

This quarterly clinic was launched in November 2008 to fulfill a recommendation from CREST (2008), with a remit to provide a specialist assessment and investigation unit for patients who require additional medical investigations and a more in-depth medical assessment and plan. The clinic team consists of:

- ▶▶ A medical consultant from palliative care, dermatology and vascular surgery
- ▶▶ The five trust lead lymphoedema specialists
- ▶▶ The regional LNNI lead
- ▶▶ The regional project manager.

An evolving clinic policy guides the governance and administration arrangements. The outcomes of the clinic are also themed and will eventually influence the revised referral criteria and address educational competencies.

### Website launch: [www.lnni.org](http://www.lnni.org)

The LNNI website was launched in October 2008 and acts as a communication and educational tool. Stakeholders can register online and access all network signed-off reports, as well as receiving information via an e-mail distribution list.

### Personal and public involvement (PPI) activities

The board patient representatives have led, in conjunction with the project team, the involvement of patients from across Northern Ireland in the overall project. This has included:

- ▶▶ Patient/user focus groups
- ▶▶ Patient questionnaires
- ▶▶ Development of new patient awareness leaflets
- ▶▶ Stakeholder event
- ▶▶ Presentations and educational sessions.

PPI is key to all board activity and is recognised as a core part of the modernisation of regional services. The two stakeholder events held in the first year have provided guidance for further involvement of the project.

### Minimum dataset — LymphDat

The board agreed to sponsor a new regional minimum dataset that will be

used to record key information for the service. This tool is currently in the developmental stages but when populated will provide information for audit, research and future service development. The tool will also provide formalised letter formats to improve standardised communication with referrers and other stakeholder groups.

### Education — under and postgraduate

The education strategy formalises the three-year plan for education at various levels, including under and postgraduate, PPI and project board and team. This supports the ethos of the network with training ranging from basic awareness information, leaflets and posters to formal accredited programmes for specialist management.

The undergraduate programme, developed in conjunction with the University of Ulster, was piloted in June 2008 with nursing students. The feedback has been evaluated and is being used to adapt and shape the teaching format. The current format includes a formal lecture and web-based learning. This will evolve to include video links to examples of complex decongestive therapy (CDT) and patients telling their own case stories. In order to follow the recommendation of the 2004 review, it is planned to roll this out to the undergraduate programmes for allied health professionals, clinical psychologists and for medicine.

An essential element of the education programme is the planned awareness campaign. New patient information leaflets and posters have been developed to raise the profile in all care settings. The posters have four designs, two for cancer and two for non-cancer. One of each sub-group is directed at healthcare professionals, and the other at potential 'at risk' patients. Each of the trust leads also has a programme of lymphoedema awareness planned to run over the next year in all areas of potential referral. This is supported by regional study days to provide more in-depth learning for those acting as ward or clinic link staff.

### Influencing and lobbying

The project team has been involved in designing specific information for the regional Cancer and Cardiovascular Framework Standards. Both documents highlight the need for timely patient information, provision and onward referral. Performance indicators have been agreed to audit this activity. Associated work has led to a further development of the cancer minimum datasets for breast and gynaecological tumours, and the inclusion of a section for pre and post-surgery limb volume measurements, as a means of highlighting a physical change and action early referral to a clinic. It is hoped that these formal documents, together with the awareness training, will ensure early diagnosis and treatment, thus increasing the opportunity to potentially return the patient to a latency stage of the condition. This form of close monitoring is already used in Australia and America and has been shown to be extremely effective and efficient. LNNI have secured research funding from Friends of the Cancer Centre (Belfast) to assess the feasibility of running similar full screening programmes in the province.

The network has also been lobbying members of the local government, including the Health Minister and acting Chief Medical Officer, to continue to raise the profile. LNNI have recently joined the Long Term Conditions Alliance Northern Ireland (LTCANI) in support of the drive to highlight the need for improved management of chronic diseases.

The network has also engaged with the British Lymphology Society (BLS), and more recently, the International Lymphoedema Framework (ILF), and has been stimulated by the activity generated by both of these bodies.

### Trust governance arrangements

Each of the five HSC trusts has a clinical lead for the new service, of which fifty percent of the time is dedicated to clinical management, and the remaining to service development and network activities. This job

description was agreed to ensure that protected management development and teaching time was available to the leads. While key link directors have been identified for each trust by the board, the leads have also established a clinical team and a wider governance team. The latter has senior management representation plus members from all potential stakeholder groups (i.e. tissue viability, dermatology, DVT services, podiatry, breast cancer, gynaecology/urology cancer, etc) to ensure partnership and inclusivity with intra-trust growth.

The leads and board patient representatives have also engaged with other service users to identify potential changes from a patient and carer perspective. This is currently allowing the development of intra-trust patient groups to join project teams and lobby both for trust and wider services.

### Summary

The current economic climate has made this a difficult time to launch and develop a service. The £500,000 funding for the network included £60,000 for staffing and running of the network (and for the new complex assessment clinics), plus funding for a clinical lead in each trust (Band 8A), and some additional clinical and clerical support. It is recognised that this is only a starting point, and the outcomes from the network's projects will inform a business case for the Department of Health which will specify:

- » Access and resource inequalities
- » Educational requirements
- » User group feedback
- » Epidemiology (local) information.

Having identified local inequalities, this document will propose the plan for future regional development to sustain the increasing number of referrals and requirement for lifelong management. The innovative use of a managed clinical network has supported all of the coordination, design and preparation required to focus on a five to 10-year plan to achieve a cost-effective, efficient, flexible and modern lymphoedema regional service. JL

### Key points

- » A managed clinical network harnesses scarce resources and forms alliances with remote services allowing coordination and alignment, and provides the skills of leadership and project management.
- » A trust lead with dedicated non-clinical time ensures partnership across all potential referring professions working with at risk patient groups, which must be matched with user representation and a direct link to senior trust management.
- » Early detection via education, awareness and screening is critical to address the issue of escalating prevalence rates for this chronic condition; all opportunities to prevent lymphoedema must be considered.
- » A minimum dataset is essential for all services to truly understand the nature and degree of the workload, and thus be informed for future service development — both for funding and organisation of services to meet need.

### References

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