



Lymphoedema Network Northern Ireland (LNNI)

Annual Report 2015/16

Agreement Cover Sheet

This annual report has been prepared by:

Chair of LNNI Board

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Date agreed May 2016

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Date agreed May 2016

LNNI Board members agreed the report on

Date agreed 31st May 2016

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Introduction

In 2002 the Chief Medical Officer commissioned a review of regional lymphoedema services: The Report of the Lymphoedema Services Review Group (2004). The Lymphoedema Network Northern Ireland (LNNI) was launched in 2008 with a vision to change the emerging picture of the condition. This work is supported by the cardiovascular and cancer service frameworks and regional and national strategic drivers.

The LNNI Board has continued to provide an executive platform regarding leadership and direction to the work of the network whilst ensuring that all those with lymphoedema in Northern Ireland have equal access to high quality person centred care.

The project team have continued to review the work plan, demand and capacity. Modernisation continues to follow Transforming Your Care principles with the establishment of controlled patient discharge utilising increased self-management skills and GP supervision (with access into the system as required). The teams have been auditing re-referrals and addressing patterns; to date there have been few, suggesting a positive response from both service users and primary care.

The team also continues to address new challenges, such as the increasing number of referrals for babies born with lymphoedema, and is developing partnerships with other professional groups regarding vascular assessment, genetics and coronary team education.

LNNI has continued to extend its links both nationally & internationally. The management team have continued to assist senior HSE teams to develop and inform their plan for a clinical network development with potential for cross-border working. The network has also been recognised by the British Lymphology Society (BLS) as the LNNI policy for management of patients with obesity related lymphoedema has become the foundation of what is now a national publication. The BLS tariff publication also reflects the regional long term condition paper. This was presented at the International Lymphoedema Framework meeting which is a significant accolade regarding service design and management.

For decision making / approval 60% of key members with a minimum of one patient representative, one trust clinical lead and one member from the management team must be present. All 2015/16 meetings achieved the required quorum.

2.0 Patient and Carer Feedback Involvement

The teams continue to work with all support groups to ensure PPI leadership and support for each trust team. The Board PPI representatives also continue to support the LNNI Network, and individual teams, to build upon experience and individual learning. The patient representatives (or alternates), attend LNNI Board meetings, participate in electronic (e-mail) document reviews/additional communications and represent LNNI at other events e.g. Long Term Conditions Alliance Northern Ireland.

3.0 Key Achievements

Throughout the 7th year:

- Excellent feedback from service user satisfaction audits across region with focus for next year's work programme
- Further streamlining of genetic clinics for those with congenital / primary lymphoedema in partnership with the BHSCT Regional Genetics' Team
- Contribution to national congenital/ primary lymphoedema register held at St George's, London.
- Commencement of use of CCG referral system for GPs
- Commencement of use of ECR

- Design of a new volume calculator with an option for App design
- Review of referral and discharge policies with associated paperwork
- LNNI Lead, (also current Chair of the British Lymphology Society) leading a National Lymphoedema Partnership to take forward the 4 country issues, share learning and promote strategic working
- Membership of the British Lymphology Society's (BLS) obesity, tariff and children's groups
- Development of regional knowledge base for managing children with lymphoedema
- LNNI Lead on committee of the Long Term Conditions Alliance Northern Ireland
- Membership of national research project looking at BCRL
- Active participation in the international Lymphoedema Awareness Week activities across the region
- Joint working with Leg Ulcer Forum and TVN Network to create guidance for vascular assessment; initial plan with BHSCT pilot to create a leg clinic to streamline cross sector care (in partnership with Directorate of Nursing)
- Progress regarding Physiotherapy independent prescribing
- Poster presentations 1st prize (expert) at national BLS 2015 annual Conference
- Submission of posters for BLS 2016 and oral presentation planned
- Acceptance of poster presentation for National Chartered Society of Physiotherapy Conference, Oct 2015
- Oral presentation at regional AHP Leadership conference, January 2016
- Cross border relationships strengthened with preparation for HSE Lymphoedema Network
- Redevelopment of website www.lnni.org with an emphasis on providing patient information and healthcare education opportunities
- Launch of new patient information re returning to work and coping at home designed by our service user group, and new literature being developed for skin care guidance and basic self-care in an Easy-read format
- Regional complex clinic: only 1 clinic required in 2013/14/15 in acknowledgment of the up-skilling of the physio teams with the development of local trust support resources.
- Out of area surgical assessment completed with HSCB funding
- Continued use of minimum data set to inform reporting, including review of new cardiovascular framework
- Continued lobbying regarding key issues affecting the service e.g. increasing levels of obesity and access to bariatric services etc.
- Creation of a lymphoedema Palliative Care commissioning brief as part for the regional AHP Palliative Care Forum
- Work with the PHA to improve prescribing skills via GP electronic systems and manufacturer formats, plus education for community pharmacists.

4.0 Key Challenges for 2015/16

- Vacancies**
The teams have again been faced with a very difficult year due to maternity and sick leaves (with no backfill) together with unfilled vacancies and slow recruitment. This has severely limited opportunities to develop teams as all available staff have been utilised for clinical purposes in order to keep meeting the 13 week AHP access target.
- Continued Increase in Incidence :**
The research based estimation of this patient population has changed dramatically since the 2008 LNNI launch:
 - In a 2008 publication - 1.3 per 1000
 - In a 2012 publication - 3.99 per 1000

The referral rate continues to be higher than expected with 1341 new contacts in 2015. The 1st January 2016 LNNI prevalence figure is 7033 (from figures collated from 2010) and 3.9 per 1000 population; this is more than double the anticipated 2008 prevalence and reflects the 2012 research publication data.

The team have focused on increased self-management skills for all suitable patients and have instigated a discharge to care of GP programme for those that are able (with fast track access back if needed); this has reduced the number of reviews and hence some of the pressure from the increasing incidence. As a result, reviews numbers dropped regionally by 1284 in 2014 and a further 332 in 2015. Re-referrals back into the service are audited and addressed by trust.

iii. Population change:

The increasing number of referrals for children and new babies is a challenge to a service created and funded to manage adults. The team have worked to develop new skills and links with national and international bodies to inform practice.

Lipoedema is a condition which, whilst appearing similar in physical appearance to lymphoedema, has a differing pathology. The teams are not specifically funded to manage this condition but have 70 patients on the caseload; the patients have no other service option available to them currently. The LNNI team continue to support this patient group as able, and are developing links with national support groups.

The new (non-cancer) population continues to become more complex and chronic. Multiple co-morbidities exist requiring longer treatment periods and more joint working with other teams such as tissue viability. The team is developing this work with tissue viability colleagues to investigate new models of working.

iv. Obesity issues:

This new adult lymphoedema population have much higher BMI scores than the average population. The team piloted 2 physical activity schemes for those with a BMI over 30 (in partnership with Active Belfast and in the Western Trust); despite a full complement commencing the classes, the dropout rate was very high. On review, it was felt that counselling or psychological services were required alongside the activity programme. It continues to prove difficult to access psychology services in all trust areas.

The management of this group is made more complex by the health and safety aspects requiring correct handling equipment, additional support staff and domiciliary care. The role of the band 3 support worker is being utilised to reduce risk where possible, however not all trusts have access to this staff grade.

v. New technologies:

Numerous new technologies are entering the lymphoedema market to support established care. The LNNI clinical team have purchased deep oscillation devices that have proved to be useful regarding self-management. Another system, PhysioTouch, was very successfully piloted in August 2015 and a bid for purchasing submitted in December 2015 by the PHA under the e-health programme.

vi. Cancer survivorship:

Patients with cancer are living longer due to the developments in cancer management. The leads are working with the Transforming Cancer Follow Up teams re preventative education and referral information, and with regional survivorship education leads. Referral patterns demonstrate that earlier referrals are being made for this patient subgroup.

5.0 Future modernisation for 2016/17

The network continues to utilise data, national/international practice and patient feedback to focus its work plan to continue to increase effectiveness and efficiency.

- i. Long term conditions model, supported self-monitoring and discharge:
The network has reviewed the 2012 DHSSPSNI Long Term Conditions Framework and aims to continue to increase the active role of the patient to one of shared partnership with the healthcare staff. This supports the 2015 Donaldson recommendations.

Facilitated discharge is now normal (with fast track re-referral if necessary) however-referrals are being audited to assess the pathway change and address referrer education issues. Additional treatment adjuncts are being trialled such as hydrotherapy and exercise classes.

- ii. Team Skill mix development
The team leads have been working with their band 3s to up-skill to facilitate basic care. This may evolve to a band 4 and work has been started to look at job descriptions and competencies. This will also be addressed as a national project via the BLS.
- iii. App potential
The network is investigating the development of a limb volume calculator App and is in discussion with the PHA and UU. An Excel model has been developed for the min data set and may be transferable. Other Apps are also in development across the UK and it would be hoped that with the increased use of mobile devices that they may become part of regional use.
- iv. Independent Prescribing and risk reduction
The WHSCT Lead, Jill Hamilton, has completed the AHP Independent Prescribing programme, and a second specialist in the SHSCT is currently completing the qualification. This achievement has raised an issue regarding funding of items prescribed. All trust teams have audited their potential prescribing activity (costs) and the LNNI Lead is liaising with the AHP commissioner prescribing Lead regarding national guidance and progress. Currently costs are shared with primary care, however first line prescribing would increase the efficiency of the teams and improve patient care.

The teams are also completing Datix incident reports for all damaged/incorrect deliveries to raise the profile of this issue with relevant companies.

The LNNI Lead is also working with the PHA to increase GP and Pharmacy awareness re prescribing of compression garments in line with the regional plan to site Pharmacists in GP surgeries. Work continues to also identify means to increase prescribing accuracy via product code identification (where possible).

- v. Paediatrics and related genetics assessment:
The team will continue to build upon the 2014/5 work to engage with families to foster support networks and shared learning. All families, and those with identifiable primary lymphoedema, will be encouraged to attend specific lymphoedema genetics clinics to aid both regional and national research and mapping. Links with the national children's group will be strengthened. Families are encouraged to link with the national paediatric group and to attend the bi-annual "Lymphatics" family day.
- vi. Shared working:

The team have started work with the regions TVN and Leg Ulcer Forum teams to develop a regional partnership to improve primary care vascular services including the further education of district nursing. Potentially this might expand to become a national project.

- vii. Furthering prevention role:
The network actively promotes awareness/prevention activities related to cancer treatment. The minimum data set has highlighted the increasing referral rate as a result of other conditions/management. There has been progression regarding the correct use of compression post-VTE/DVT with both regional audit and education, but other areas are now open for education:
- Infectious diseases
 - Emergency departments
 - Neo-natal care (including the development of the new regional network)
 - Looking at new and developing non-Caucasian population groups as referral patterns suggest a lower than expected referral rate from these cultural groups.
- viii. Surgical developments:
Recent improvements in lymphoedema liposuction have made this a viable option for some patients who develop abnormal fat deposits as a result of associated inflammation. This is not currently available regionally. The number of patients requiring this surgery is still low, but some success has been achieved regarding out of area funding for assessment. The team has investigated the potential for accessing a Scottish consultant regarding one assessment clinic per year in Belfast; however this has not proved possible. The team will continue to monitor research and practice changes to inform the LNNI Board and management options.
- ix. Developing national/international linkages:
The network is continuing to develop links with the British Lymphology Society and is influencing the work plan of this national group, regarding obesity, tariff and paediatrics in particular. Other links include the national Lymphoedema Support Group, Macmillan and the Chartered Society of Physiotherapy which provide education opportunities. The network also links with the Welsh and Scottish project leads.

The network is a member of the UK and Ireland's National Lymphoedema Partnership, and will participate in national activities to promote governance and performance. This national body also has membership from the International Lymphoedema Framework ensuring access to a wider stakeholder group.

For further information on the LNNI Board, please follow this link: www.lnni.org