Lymphoedema Network Northern Ireland (LNNI)

Annual Report 2016/17

Agreement Cover Sheet

This annual report has been prepared by:

Chair of LNNI Board

Name: Ms Michelle Tennyson

Date agreed May 2017

LNNI Project Lead

Name: Ms Jane Rankin

Date agreed May 2017

LNNI Board members agreed the report on

Date agreed 13th June 2017

Annual report review date: AGM, June 2018

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. The network has operational links with the DoH, HSCB and PHA, and work is supported by the cardiovascular and cancer service frameworks, and regional and national strategic drivers.

The LNNI Board welcomed Ms Michelle Tennyson as its new chair in July 2016, and 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. Mr Roger Kennedy representing the HSCB also joined the network in February 2017.

The project team have developed a 2017/18 work plan following Transforming Your Care principles, and will:

- Quantify current demand and referral routes
- Quantify the impact of changing demographics (particularly: chronic oedema, palliative care, obesity, lipoedema and paediatrics)
- Pilot and review self-management systems in partnership with other agencies
- Roll out education and communication strategies
- All-Ireland cross border working

LNNI has continued to extend its links both nationally and internationally. The management team have worked closely with the HSE project lead to develop and inform their plan for a clinical network development with potential for cross-border working. This includes the inaugural All-Ireland conference on 15th November 2017 and a joint certification course in October 2017. The network has also been recognised by the British Lymphology Society (BLS) regarding its successful communication strategy aimed at increasing the awareness of healthcare professionals regarding lymphoedema; this is now being updated to include lipoedema awareness. LNNI Board agreed to support the attendance of 2 leads at the June 2017 International Lymphoedema Framework conference, to continue to develop international networks and build upon research.

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 2016/17 meetings achieved the required quorum.

2.0 Patient and Carer Feedback Involvement

The teams continue to work with support groups to ensure PPI leadership and support for each trust team. The Board PPI representatives 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 and participate in electronic (e-mail) document design and reviews.

3.0 Key Achievements

Throughout the 8th year:

Electronic/technology:

- Design of a new App for volume/BMI calculations with an option for stage 2 development to enhance for patient use (PHA funding bid re stage 2 submitted February 2017) in partnership with the UU and PHA (Stage 1 to be launched at All-Ireland conference)

- Launch of updated website www.lnni.org with an emphasis on providing patient information and healthcare education opportunities (including a new lipoedema webpage)
- Electronic developments: link with CCG and LCID (SEHSCT initially), potential for H&C Index link to Lymphdat being investigated (and proposal for gradual move to full electronic record)
- All trusts now have access to PhysioTouch to support advances in technology; LNNI also supported the purchase of three Toe brachial pressure index machines to aid vascular assessment

Governance/ service development:

- Launch of guidance for vascular assessment (Joint working with Leg Ulcer Forum and TVN Network)
- Launch of PHA led pharmacy and GP garment ordering guidelines, supported with a patient information statement
- Work with the PHA to improve prescribing skills via GP electronic systems and manufacturer formats
- Creation of a lymphoedema Palliative Care commissioning brief (including regional audit) as part for the regional AHP Palliative Care Forum's evidence based symptom management publication (launch summer 2017)
- Initial plan with GP Federation/BHSCT re pilot to create a leg clinic to streamline cross sector care (in partnership with Directorate of Nursing)
- Progress regarding Physiotherapy independent prescribing
- Development of new governance paperwork to address specific risk assessment
- Review of referral policy and associated paperwork
- Regional agreement of a band 3 and 4 competency document to supported enhanced skill mix (and in conjunction with a national working group); a bid was made to the PHA to support this change, but no funding available to date
- Continued development of regional knowledge base for managing children with lymphoedema
- Contribution to national congenital/ primary lymphoedema genetic register held at St George's, London
- Development of new patient information re compression bandaging and self-monitoring, and updating of exercise and simple lymph drainage leaflets taking new evidence into account for updates
- Regional complex clinic: only 1 clinic (October 2015) required from 2013/14 in acknowledgment of the up-skilling of the physio teams with the development of local trust support resources
- Out of area surgical assessments 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.

Awards/recognitions:

- Winner of 2016 British Lymphology Society (BLS) national award for raising awareness of healthcare professionals including the active participation in the international Lymphoedema Awareness Week activities across the region
- Poster presentations 1st prize (expert) won by a BHSCT clinician and 1st prize (novice) won by the WHSCT lymphoedema lead, at national BLS 2016 annual Conference
- SHSCT 2016 winner of Chairman's award with funding to pilot a self-management group (review 18th October 2017)
- SEHSCT Lead and Assistant (band 3) were Runners Up at the 2017 National AHP Advancing Healthcare Awards in the category regarding the enhanced role of physiotherapy assistance (in the development of an aqua therapy scheme for patients)
- WHSCT Lymphoedema Lead is the winner of the trust's AHP inaugural award for "Going beyond the call of duty" and nominated by the mother of children under her care (2017)

Links with other Bodies:

- Cross border relationships strengthened with preparation for HSE Lymphoedema Network including inaugural All-Ireland conference (15th November 2017) and All-Ireland Foldi/Klose certification training course (October 2017)
- LNNI Lead chairing the National Lymphoedema Partnership to take forward the 4 countries' issues, share learning and promote strategic working
- Membership of the British Lymphology Society's (BLS) obesity and vascular groups
- Membership of the Children's Lymphoedema Special Interest Group
- LNNI Lead on committee of the Long Term Conditions Alliance Northern Ireland
- Membership of national research project looking at BCRL and an international study regarding laser
- Links with Talk Lipoedema and Lipoedema UK charities (including actively participating in the new UK lipoedema guideline development – launched spring 2017)

4.0 Key Challenges for 2017/18

i. 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 2016 audit of referrals shows this to be 4.83 per 1000

The 2016 figure is more than 3 times the anticipated 2008 prevalence and reflects the 2012 research publication data, and also the current Welsh figures.

The introduction of the electronic CCG referral has in particular had a significant impact, especially in the NHSCT where waiting times have breached throughout 2016/17; LNNI Board agreed to provide temporary finance to provide additional clinical hours to allow local resource evaluation (intra-trust) in the January-March 2017 period.

NHSCT Waiting statistics	**2015**	**2016**	**2017**	**Increases in referral numbers and time waited (2015-2017)**	**Comments**
January	26 referrals waiting 8 weeks	70 referrals waiting 13 weeks	106 referrals waiting 24 weeks	X4.07 referral increase and x3 time period	LNNI funded 8 additional hours per week from 1st Jan-31st Mar 17
February	25 referrals waiting 8 weeks	64 referrals waiting 15 weeks	81 referrals waiting 25.4 weeks	X3.24 referral increase and x3.17 time period	
March	25 referrals waiting 8 weeks	55 referrals waiting 17 weeks	87 referrals waiting 29.4 weeks	X3.48 referral increase and x3.67 time period	Easter and annual leave taken

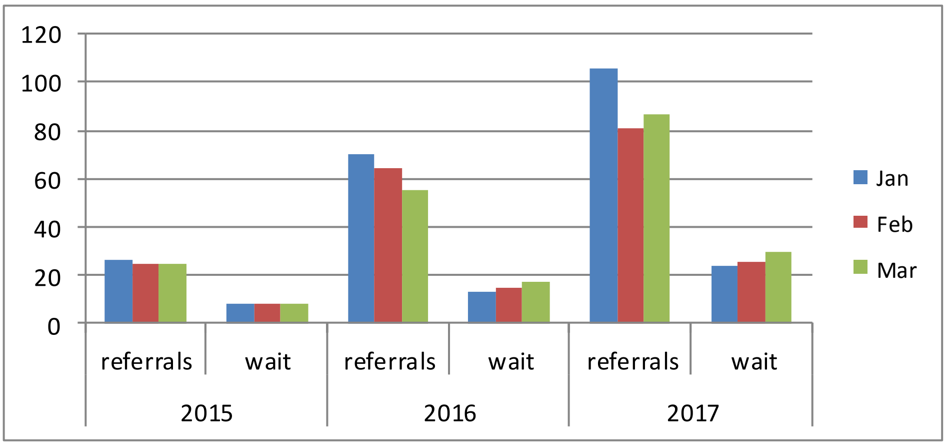

Figure 1: NHSCT Referral numbers and waiting times (weeks)

The teams have continued to focus clinical triaging and on increased self-management skills; several pilot groups have been initiated.

ii. Population change:
The increasing number of referrals for children and new babies is a challenge to a service created to manage adults. The team have worked to develop new skills and links with national and international bodies to inform practice. Links have been created to the new dedicated Welsh paediatric lead and the network will address the new children's charter when launched (summer 2017).

Lipoedema is a condition which, whilst appearing similar in physical appearance to lymphoedema, has a differing pathology. The LNNI team continue to support this patient group as able, and have developed 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.

The network has also recorded a new increase for simple chronic oedema referrals, and has amended their CCG banner to focus only on the complex cases; as such, simple oedema referrals should be managed by practice and district nursing. A draft business case has been presented to the Belfast GP Federation suggesting a nurse-led simple chronic oedema clinic which could also support garment review and re-order for the lymphoedema services; it is for review at present.

iii. 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 with the SET and local leisure centres. The Belfast class had a high dropout rate, but has been reviewed and modified for a second pilot with increased self-efficacy direction. The SET team has embedded an HSC aqua-therapy group which has produced promising results; it had designated follow-up band 3 time dedicated to encourage continued participation. 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 network will need to continue to lobby for recognition of impact of obesity.

New relationships have been developed with diabetes teams to investigate the utilisation of the Desmond (Diabetes self-management programme as many of this patient group also have diabetes), and access to the specialist diabetes physical activity resource.

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.

iv. New technologies:
Numerous new technologies are entering the lymphoedema market to support established care. The LNNI clinical team have piloted and purchased PhysioTouch devices and Toe Brachial Pressure assessment tools. LNNI will continue to monitor the development of technology, initially at the June 2017 ILF conference, and throughout 2017/18.

v. 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. There appears to be an increase in the number of head and neck cancer referrals, perhaps due to a new specialist physio post which has raised on site (RVH –ENT) awareness and triaging.

5.0 Future modernisation for 2017/18

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. Facilitated discharge is now normal practice (with fast track re-referral if necessary) however- referrals are being audited to assess the pathway change and address referrer education issues; to date, this is a successful process. Additional treatment adjuncts are being trialled such as hydrotherapy and exercise classes. This supports the 2015 Donaldson and 2016 Bengoa recommendations.

ii. Team Skill mix development
The team leads have been working with their band 3s to up-skill to facilitate basic care. This is evolving to band 4 level (unsupervised for specific patients), and new competencies have been created (in conjunction with a national project). Methods of providing this new band 4 care are to be investigated.

iii. App potential
The network is developing a limb volume/BMI calculator App with the PHA and UU. An Excel model has been developed and screen shots created. UU students are developing the App programming.

iv. Independent Prescribing and risk reduction
Three staff have completed the AHP Independent Prescribing programme. This achievement has raised an issue regarding funding of items prescribed, and also potential progression whilst the HECR is developed.

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 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:
All families, and those with identifiable primary lymphoedema, continue to be encouraged to attend genetics clinics (one-to one referrals) to aid both regional and national research and mapping. Links with the national children's group will be strengthened, and the national Charter adopted once launched. Families are encouraged to link with the national paediatric group and to attend the bi-annual "Lympaletics" family day.

Links with other dedicated paediatric posts/services will be strengthened nationally, and the network will focus on building links with physiotherapy paediatric services, especially neuo-disability.

vi. Shared working:
The teams are working across the region with colleagues from TVN and Leg Ulcer Forum contacts to develop a regional partnership to improve primary care vascular services including the further education of district nursing, practice nurses and GPs.

Partnerships with GP Federations for both service provision and education are being established.

vii. Furthering awareness provision role:
The network actively promotes awareness/risk reduction activities. The minimum data set has highlighted the increasing referral rate as a result of other conditions/management. Areas open for education:

- Paediatrics
- Palliative Care
- Head and Neck cancer services
- GP practices: GPs, pharmacists and practice nurses
- 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 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. On average, there are 4 assessment referral requests per year.

ix. Developing national/international linkages:
The network is continuing to develop links with the British Lymphology Society, International Lymphoedema Framework, National Lymphoedema Partnership, Lymphoedema Support Group, Macmillan and the Charted Society of Physiotherapy which provide education opportunities. The network also links with the Irish, Welsh and Scottish project leads.