Lymphoedema Network Northern Ireland (LNNI)

Annual Report 2017/18

Agreement Cover Sheet

This annual report has been prepared by:

Chair of LNNI Board

Name: Ms Michelle Tennyson

Date agreed June 2018

LNNI Project Lead

Name: Ms Jane Rankin

Date agreed June 2018

LNNI Board members agreed the report on

Date agreed 15th June 2018

Annual report review date: AGM, June 2019

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 regional and national strategic drivers.

The LNNI Board, with chair Michelle Tennyson, 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 developed a 2018/19 work plan following Transforming Your Care and Bengoa 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 clinical network engagement and cross-border working. This included the extremely successful inaugural All-Ireland conference on 15th November 2017 and a joint certification course in October 2017.

The LNNI Board has also continued to develop relationships with the (ILF) International Lymphoedema Framework, and supported the attendance of two trust leads at the June 2017 conference in Sicily and one at 2018 conference in Holland, to continue to build practice 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 2017/18 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 9th year:

Electronic/technology:

- Design and development of a new App for volume/BMI calculations; currently in final test mode. A 2017 grant proposal bid was submitted to the PHA for stage 2 development to enable patient use; however this awaits the return of a regional government regarding decision and potential implementation.
- A recent new philanthropic contact, a specialist in health technology, has volunteered to convert our PDF patient information leaflets into App formats and to create an e-library resource.
- Electronic developments:

  - Link with CCG and LCID (SEHSCT)
  - H&C Index linked to Lymphdat to pre-populate demographics from PAS (and gradual move to full electronic record for those trusts that have mobile electronic devices)
  - PARIS (BHSCT) populating ECR with basic lymphoedema management information
- All trusts now have access to Toe brachial pressure index machines to aid vascular assessment; LNNI purchased additional equipment with end of year monies.

Governance/ service development:

- 2016 vascular assessment/ agreement regarding use of Doppler (Joint working project with Leg Ulcer Forum and TVN Network) was shared with BLS and is being developed as a national document
- Following the 2017 launch of the PHA led pharmacy and GP garment ordering guidelines, there has been increased liaison with the pharmacy education team linked with the new GP Practice Pharmacists; this has resulted in a project ECHO education seminar for all regional practice staff (June 18)
- Work continues to improve prescribing skills via GP electronic systems and manufacturer formats with positive outcomes achieved. This is an on-going piece of work and is supported by audit and the learning from the four senior physiotherapists who are non-medical prescribers.
- Successful LCG bid in SEHSCT with lymphoedema, TVN and pharmacy teams regarding GP practice nurse education project
- Progression of SHSCT project for patient education programme; this has been extended to include education for trust staff
- Continued discussion regarding plan with GP Federation/BHSCT re pilot to create a leg clinic to streamline cross sector care (in partnership with Directorate of Nursing)
- New links with pre-diabetic transformational working group to enhance referrals and self-management
- New psychology links with projects proposed for 2018-19
- New project with PHA to inform potential referring groups regarding lipoedema awareness; this has resulted in some trusts being invited to speak at both Health Visitor and School Matron meetings
- 2018 Launch of regional AHP Palliative care Symptom Management document which includes a lymphoedema section; this is part for the regional AHP Palliative Care Forum's work plan which has also included a workforce review. LNNI has participated in both aspects of the project.
- New intra-trust genetic contacts made as part of contribution to national congenital/ primary lymphoedema genetic register held at St George's, London
- Continued use of regional band 3 and 4 competency document to supported enhanced skill mix and training (and in conjunction with a national working group). No funding has been found to date to support this progression. The BHSCT have one post submitted for job evaluation.
- Continued development of regional paediatric database and knowledge base. This has included the development of specific referral and assessment protocols for children.
- LNNI has supported two families to travel to the 2018 Lymphaletics
- Continued use of patient register to inform reporting, and in particular the impact of obesity, diabetes and arthritis on this service
- Continued lobbying regarding key issues affecting the service e.g. increasing levels of obesity and access to bariatric services etc.
- LNNI supported health and safety by purchasing more bariatric equipment for the teams
- Review of LNNI patient information leaflets as per review dates
- Development of new governance matrix to address specific risk assessment
- Review of referral policy and GP CCG guidance updated
- Regional complex clinic: the last clinic was October 2015; this acknowledges the up-skilling of the physio teams with the development of local trust support resources. Updated vascular clinical guidance provided by consultant to ensure best practice (February 2018).

Awards/recognitions:

- Four posters were finalists at the September 2017 Advancing Health Care Awards
- A member of the BHSCT team was a project finalist in the September 2017 Advancing Health Care Awards regarding her breast cancer pre-habilitation project
- Two SEHSCT posters accepted for the ILF conference
- WHSCT Lymphoedema Lead was successful at the trust's Dragon's Den event and is working to develop a business case.

Links with other Bodies:

- New links with third sector bodies and relationships developed to engage and co-refer between services, e.g. DESMOND diabetes care and Arthritis UK, in respect of the recorded co-morbidities observed and common themes regarding self-management
- Cross border relationships strengthened with preparation for the Health Service Executive (HSE) Lymphoedema Network including the extremely successful inaugural All-Ireland conference (15th November 2017) and All-Ireland Foldi/Klose certification training course (October 2017)
- National Lymphoedema Partnership (NLP) joint working to take forward the 4 countries' issues, share learning and promote strategic working
- Membership of the British Lymphology Society (BLS)
- Membership of the Children's Lymphoedema Special Interest Group (CLSIG)
- Active relationship with the International Lymphoedema Framework (ILF)
- LNNI Lead on committee of the Long Term Conditions Alliance Northern Ireland
- 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 2018/19

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 2017 audit of referrals shows this to be 5.73 per 1000

The 2017 figure is more than 4 times that anticipated in 2008. The current Welsh figures is 8 per 1000, however this service has been in existence for much longer.

The introduction of the electronic CCG referral continues to impact alongside the additional new referral types (as per section ii: e.g. paediatrics, chronic oedema and lipoedema) and the impact of obesity (section iii). This is especially noted in the Northern Health and Social Care Trust (NHSCT) where waiting times have breached access targets from 2016; the LNNI Board provided temporary finance to provide additional clinical hours in early 2017 and the trust has provided temporary funds for the service from December 2017, and on-going. This has improved access to the service, however the Trust lead is still not able to function at the designated clinical: management ratio. A capacity and demand exercise has been completed for the trust with the PHA and recommends an increase in staffing for the NHSCT service.

The average new assessment ratio to additional treatment sessions is 1:5.8 however this varies across the region and is dependent upon the referrals types. The NHSCT would more reflect the Belfast figures which are 1:7.69. It is recommended that the NHSCT increase their team by 1.5wte according to these averages, and dependent upon their numbers breaching the waiting list.

Ratio	Correct job plan and patient assessment capacity	No of Patients who cannot be assessed with current staffing and correct job plan per average year	Additional staffing required to meet demand
1:6	135 pts per yr	185	1.37 wte (bd 6 /7)
1:7	118 pts per yr	202	1.71wte (bd 6 / 7)
1:8	105 pts per yr	212	2.02wte (bd 6 / 7)

An additional check was completed using the British Lymphology Society tariff calculations and this also agreed that an increase in 1.5wte was required to meet the demand.

Additionally,

- The Welsh Lymphoedema Network has 1 Healthcare professional per 44285.7 head of population (with 70 staff and a population of 3.1 million); Wales also received recent funding for a new full time Specialist Paediatric post and an education and research post.

- LNNI has 1 Healthcare professional per 118421.05 head of population (with 15.2 staff and a population of 1.8 million)

All trust teams continue to focus clinical triaging and on increased self-management skills; several pilot groups have been initiated as highlighted on page 3.

ii. Population change:
Paediatrics: 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. LNNI has created new paediatric referral and assessment tools, and have engaged with all physio paediatric teams to raise awareness.
There are now 29 names on the paediatric register, and the majority of these cases are complex.
The teams welcomed the new national charter in autumn 2017 and been developing their teams to meet the recommendations.

Lipoedema: Lipoedema is a condition which, whilst appearing similar in physical appearance to lymphoedema, has a differing pathology. LNNI has worked with the PHA to raise awareness of lipoedema including the development of a new section on the LNNI website. Links have been made for specific education with school matrons and health visitors as these can be times when lipoedema will first be identified. Likewise there has been education with some of the diabetic teams as rapid weight gain can also cause lipoedema, and with Arthritis UK as many of this population develop joint problems.

Chronic Oedema: 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 and pharmacy colleagues to investigate new models of working. This includes upskilling of practice nurses to manage simple oedema referrals, district nurses regarding lymphorrhea management and looking at new ways to manage the population who do not require specialist lymphoedema care.

iii. Obesity issues:
This adult lymphoedema population continues to have much higher BMI scores than the average population. 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.

LNNI has had formal meetings with the psychology leads from both the BHSCT and NHSCT, but it continues to prove difficult to access psychology services in all trust areas. The lead Psychologist from the NHSCT has agreed to engage with the team regarding the LNNI “impact of obesity” paper, and will jointly develop an Innovation, Quality and Improvement submission. It has also been agreed that local support will be provided via “raising the issue “training which will hopefully roll out to all LNNI staff in late 2018.

The network continues to lobby for recognition of impact of obesity at every opportunity.

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. LNNI has linked with the Transformation group looking at pre-diabetes and has requested permission across the region to refer to this project (autumn 2018). LNNI was able to raise the need for psychology at this meeting, and it has now been included in the prevention work plan.

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. LNNI purchased more bariatric equipment for the teams in autumn 2017 to support safe handling.

iv. New technologies:
Numerous new technologies are entering the lymphoedema market to support established care. The LNNI clinical team have purchased additional Toe Brachial Pressure assessment tools. LNNI will continue to monitor the development of technology, initially at the June 2018 ILF conference, and throughout 2018/19.

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; a new specialist ENT physio post now provides awareness and triaging; this post has received temporary 2018-19 additional funding to pilot programmes, including for lymphoedema education and onward referral pathways. LNNI is trying to develop this relationship.

The breast cancer pre-habilitation awareness/self-management programmes have also been successful in the BHSCT and SHSCT.

vi. Surgical developments:
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 in previous years regarding out of area funding for assessment; however there has been no funding in 2017-18. 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.

5.0 Future modernisation for 2018/19

The network continues to utilise data, national/international practice and patient feedback to focus its work plan to continue to increase effectiveness and efficiency. Many of the 2017-18 issues and plans continue.

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, and 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; the BHSCT has a member of staff participating in job evaluation.

iii. App potential

The network has developed a limb volume/BMI calculator App with the PHA and UU. The 2017 Excel models have been developed into a draft android model which is currently being trialled regarding user technique and data checks. This will then need to be converted to Apple format.

A new health technology expert has offered his philanthropic support to produce an e-library of the LNNI patient support information; this is part of the 2018-19 work plan.

iv. Compression prescribing and risk reduction

Four 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 SEHSCT are to pilot the new service in 2018-19.

LNNI Lead is continuing to work with the trusts and 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).

Additional projects:

- The SEHSCT GP practice nurse supported education programme (in partnership with the pharmacy and TVN teams)
- The BHSCT project ECHO awareness teaching to all GP pharmacists
- The trust leads are currently re-auditing the local practice and outcomes, and addressing individual issues locally

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. Intra-trust contacts have been made via the roll out of local genetic clinics to aid attendance.

Links with the national children's group has been strengthened, and the national Charter adopted in autumn 2017. The Charter has also been shared with the regional paediatrics group aim to identify gaps and also plan for the transitional point when children leave the service for adult care.

Families are encouraged to link with the national paediatric group and to attend the bi-annual "Lympaletics" family day (September 2018); LNNI provided a small grant to two families to aid travel to this fantastic event. LNNI plan to hold a local event in the autumn.

vi. Shared working:

As per section 4.ii and 4.iii and the feedback from the patient register, the teams will continue to develop relationships with the third sector regarding self-management resources as many of this population have many co-morbidities including diabetes and arthritis. The work plan includes increasing awareness of lymphoedema/lipoedema with the local trainers to aid referrals between the services. The teams will also work to influence any transformational work linked to these bodies.

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 and Practice staff are being established.

There is continued engagement with other NHS resources to address awareness issues and support for this population including:

- Palliative Care
- Head and Neck cancer services
- Psychology

vii. 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.

The next All-Ireland Lymphoedema conference will be held at An Grianan, Drogheda, and will be run alongside a masterclass for clinical specialists in the CEC, Belfast. It was planned for June 2019 but now clashes with another international conference and hence, is currently being re-scheduled. The new HSE Lymphoedema Strategy will be published in 2018 and LNNI will continue to liaise regarding services in the border areas in particular.