



Lymphoedema Network Northern Ireland June 2021 modified Board Report

In the absence of a formal LNNI June 2021 Board meeting due to the impact of Covid 19, this modified report covers the key areas of work. The Network will plan for a December 2021 meeting, to be held virtually if Covid 19 restrictions dictate. However, before beginning the formal report, it is important to note and mark the recent retirement of Ms Elaine Stowe (NHSCT Lymphoedema Lead). Elaine was one of the first regional clinicians to become a lymphoedema expert and she will be very much missed for her expertise, kindness and dedication to those attending her clinic. LNNI has supported the NHSCT's recruitment process and is pleased to welcome Mr Kevin Campbell as the new NHSCT Lymphoedema Lead. Kevin has worked closely with both the NHSCT and BHSC lymphoedema leads, and also has a strong background in oncology physiotherapy. Kevin will visit each of the other teams as part of his induction, in order to form his first year development plan.

1.0 Covid 19 planning and adaptations

Covid 19 continues to interrupt clinical activities and has necessitated new ways of working. The project team developed a guidance document regarding safety of practice and communication in April 2020, which evolved with learning. All services are once again running face-to-face clinics for those triaged to require this type of intervention; however, some level of virtual assessment/re-assessment will remain as this has proved to be acceptable by both service users and clinical staff, and to be efficient and effective for some aspects of care. All trust leads and their teams have worked extremely hard to provide this flexible service.

The role of supported self-management has also never been stronger. Some of the teams had staff re-deployed again for the second and third waves, and this has effected waiting lists. The teams have used all forms of communication to work through waiting lists, and to improve supported self-management alongside tailored compression, and the overall waiting times for first appointments have been greatly reduced. The teams have been able to use time, normally allocated to face-to-face complex decongestive therapy, to address greater numbers of initial assessments and treatments. Compression garment technology has also dramatically improved, and is recognised as a dynamic form of management. Likewise, the Velcro wrapping devices and new generic nighttime compression systems have proved invaluable. Now that the trusts are gradually increasing the number of permitted face-to-face appointments, those requiring complex management will be contacted.

Numbers breaching (>13 weeks) waiting list for first assessment and treatment	April 2020	April 2021
	323	27



2.0 Lymphdat re-write

LNNI developed the first lymphoedema e-minimum data set 'Lymphdat' (2010), which has helped to populate many work plans and service developments. This is however, now provided on what is an aging e-platform. To ensure data security and ability to maintain continued information resources, LNNI commissioned a Lymphdat (short form (SF2)) re-write. This resource utilises nationally agreed minimum data criteria and has significant reporting options. It was developed in the autumn, but has since been further refined in partnership with a pan-London community of practice. It was internally reviewed in early 2021, and externally in late spring. The new system is awaiting BHSCT technical platform development before launch. A blank copy of this format will also be available on the LNNI website for others to download and use independently for their own data analysis, and in particular for joint HSE work. LNNI has been accepted to present this development at the British Lymphology Society (BLS) Annual conference.

3.0 All Ireland Lymphoedema guidelines (2021)

LNNI members were actively involved in the creation of the CREST Lymphoedema guideline (2008) but there have been many technology and practice developments from 2008. LNNI has worked in partnership with the Health Service Executive (HSE) Lymphoedema project team from November 2019 to jointly fund and develop a new All-Ireland Lymphoedema guideline.

During 2020, the academic review work progressed within the guideline development group and wider working groups, supported by a large group of senior clinical staff, experienced service users and a research team. I would like to thank LNNI Board member Ms Carolyn McKeown for joining the development group as a service user with many years' experience. LNNI would also like to thank another group of parents (non-Board members) who have agreed to join the external review to ensure that all aspects of paediatric care are covered from a carer's perspective. The external consultation was planned for May 2021, but the HSE cyber-attack has made what has been a Covid-challenging communication project even more difficult. An extensive group of external, multi-professional reviewers will consult on the draft document prior to final formatting. The guideline launch will be in early autumn 2021. This is an extensive piece of work for the whole LNNI team and stakeholders, and it has been fantastic working as an All-Ireland team, and continuing to build our knowledge and networks. It will also provide the framework to develop and support the new pathways highlighted at the 2018 LNNI 5 year planning workshop.

Some components of this project were sourced from recognised expert UK and Ireland resources, such as the National Lymphoedema Partnership and the BLS, plus international scientific bodies. An abstract submission regarding the development process has been completed for the 2021 BLS, International Lymphoedema Framework and ISCP 2021 conferences.



4.0 Cancer Strategy

The Cancer Strategy was discussed at the LNNI December 2019 meeting, and despite the first covid surge, the work re-focused in September 2020, and a draft consultation document is due summer 2021.

LNNI participated in drafting the 'Living Well' subgroup submissions, in particular for lymphoedema and 'Prehabilitation'. It is hoped this will improve pre-operative information provision, promote activity, good nutritional practice and supportive care, and help to risk reduce some of the potential consequences of cancer and its management. It is suggested that Prehabilitation will also be a suitable resource to gather baseline assessment data for some of the known cancer concerns, including limb volume for those at high risk of developing lymphoedema. The new All Ireland guideline has facilitated the review of risk factors to embed into this process and pathway.

A Department of Health (DOH) business case was written to support the Cancer Strategy Prehabilitation lymphoedema screening and surveillance equipment in early 2021, but was not successful. The equipment bid remains on individual trust's capital request lists.

5.0 Patient information development

The LNNI project team continually monitor and review clinical literature to ensure information provision is accurate and up to date. During 20-21 we updated the 'at risk' leaflet for those who have had breast surgery. This has taken into account new findings from NICE and been expanded to include some additional Prehabilitation information. The regional Breast Care Nurse Leads, LNNI Board Service User review group and senior Oncology Physiotherapists have been involved in this project alongside the LNNI team; it was printed and distributed in spring 2021.

Once the All Ireland guideline has been completed, LNNI will review its Easy Read documents, and begin to review Patient Reported Outcome measures (PROMs).

6.0 Education

Succession planning

At our December 2019 Board meeting, we had agreed to fund and support a regional lymphoedema certification course to support staff succession planning and ensure recruitment opportunities as the teams change. The 4-module course commenced in February 2020, but the final three modules were halted because of Covid 19. Our tutor converted more of the theory into online teaching, and the final module took place in May 2021 with DOH permission. One course place was offered to an HSE candidate, and later in the year an HSC candidate will participate in an HSE programme to support cross border working.



Specialist training

LNNI had agreed to support attendance at several international learning events over 2020. Whilst the two International Lymphoedema Framework (ILF) conferences were postponed until 2021-22, the teams were able to join the excellent virtual BLS conference in October 2020. LNNI utilised the 20/21 savings from the postponed ILF 2020 conferences to support two members from each lymphoedema team to attend the virtual Klose training course for managing Head and Neck Lymphoedema. Over the past few years we have noted an increase in the number of referrals for those with Head and neck cancer, so this was considered a prudent use of 2020/21 resources. The staff have again approached the BLS for sponsored places at the 2021 virtual conference. The ILF conference is still advertised as an attendance event, and LNNI will monitor this situation for feasible attendance dependent upon Covid 19 and travel regulations. Poster abstracts have been submitted for both BLS and ILF conferences. LNNI also has a free place at the ILF conference after winning the 2019 poster prize.

7.0 Paediatric development

In late 2019, LNNI developed a regional care pathway for children with lymphoedema, in conjunction with the Vascular Anomaly Team Physiotherapist. Discussions opened with a consultant in the Royal Belfast Hospital for Sick Children (RBHSC), St Georges NHS Foundation Trust (London) and the HSE to further develop an All-Ireland model. A RBHSC pilot paper was drafted over summer 2020, but progress halted again due to the second wave of Covid 19. Unfortunately, the RBHSC consultant retired during surge 3; hence, a new contact is to be sought. The agreed pathway is however included in the new guideline.

LNNI has developed its participation in the national group, the Children's Lymphoedema Specialist Interest Group (CLSIG), and regional anonymised data has been included in a national audit, which will help to inform and shape national children's services. The work has also facilitated the development of new paediatric assessment and re-assessment tools. Planning has started for the 2022 CLSIG 'Lymphaletics' which is a family day for those with children with lymphoedema; this promotes self-management, activity and family peer support, which LNNI will champion for local families.

8.0 Breast Cancer Services review

This work has not yet continued from February 2020 due to impact of Covid 19. Lymphoedema services and potential for at risk screening/surveillance were added to the surgical pathways, alongside Prehabilitation. Surveillance and Prehabilitation are included in the All Ireland guideline as part of a new cancer-related lymphoedema pathway.

9.0 Technology developments

Non-touch volume assessment 'LymphaTech' pilot:



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A regional business case was developed to trial new technology which can determine a fast and accurate limb volume measurement using a camera and programmed device i.e. non-touch practice. The non-touch aspect has become more vital because of Covid concerns. The SHSCT and SHSCT have accessed charitable funds for the hardware and software; trials will commence once all equipment is complete. The BHSCT has also accessed funding for the hardware. LNNI has approached a manufacturing company to apply for pilot site status for completing made-to-measure technology that integrates with LymphaTouch. The LNNI Management team has agreed to finance the teams for the first year if the pilot is successful, and requires roll out.

Non-touch garment/bandaging pressure assessment, and potentially remote monitoring research project:

LNNI has started discussions with a new post-doctoral startup company based at Galway University (engineering) to support the development of a new device to measure and monitor garment or bandaging pressures 'TightAlright'. Potentially this tool will allow clinical teams to tailor compression management to suit individuals, dependent upon actual fluid movement and associated pressure changes, and may have a remote feedback option. Discussions will expand to include local academic partners and the Welsh SMTL team who currently assess static compression pressures. This will build upon the national garment pressure work.

Weight management e-health support research project:

Bariatric problems continue to impact on services with 27% of the local population being obese and 38% overweight. As obesity is a key risk factor for lymphoedema, and worsening of the condition, this remains a key concern especially with the Covid 19 delay of the regional bariatric team development. The project team has engaged with Dr Anne Moorhead, Senior Lecturer in Health Communication (Ulster University), regarding involvement in a new e-health and weight management research project. Regional ethical permissions and project participation will start in August 2021, with an aim for service user recruitment in the autumn. This has the potential to support patients via four different e-health media, on simple wrist-mounted devices, to improve diet and general health associated factors.

Jane Rankin, LNNI Lead
1st July 2021