



Lymphoedema Network Northern Ireland December 2020 Board Report

In the absence of a formal LNNI December 2020 Board meeting, the following update covers the key areas of work:

1.0 Covid 19 planning and adaptations

Covid 19 has interrupted clinical activities and necessitated new ways of working. The project team developed a guidance document regarding safety of practice and communication in April 2020, which evolves as required. Learning has been sourced from many resources, regional, national and international to support change in practice.

All trust leads worked extremely hard to initially maintain a virtual service which, as we have learnt more, has evolved to facilitate some face to face management for those with urgent need. The teams have been impressed by how our service users have adapted too, and how very quickly virtual appointments and assessment became manageable for most. The role of supported self-management has never been stronger. The impact of the first surge, when out-patient and domiciliary services were initially halted and many team members re-located to support the wider NHS need, is still being felt and demonstrated by waiting lists.

A business case was developed to trial new technology, which can determine limb volume using a camera and programmed device i.e. a non-touch practice. The BHSCT has been successful in raising charitable funds for the hardware, and the company are providing 3-month trials of the software once the hardware procurement is complete. This technology provides a fast and accurate measurement; it will potentially support a return to more normal assessment formats. The business case is also prepared for any end of year funding opportunities for all trusts.

2.0 Lymphdat re-write, Encompass and 'Patient Portal' work

Lymphdat

In 2010, LNNI developed the first lymphoedema e-minimum data set, which has helped to populate many work plans and service developments. However, this is provided on what is considered an aging platform and, to ensure data security and our ability to maintain continued information resources, we agreed to plan and commission a Lymphdat (short form) re-write. This will be launched later in December and will provide us with a stopgap data source until all NHS Trusts move to Encompass. Encompass will build upon the successes of the Northern Ireland Electronic Health Record (NIECR), and ensure more joined up working across all services, and agreed data will be easily sourced and analysed.



Encompass should start in the SEHSCT in 2022 and roll out fully until 2024. The LNNI Management Team agreed that for this short gap period, it would be prudent to only commission the Lymphdat short form rather than full version, which would have been much more expensive. Even with the short form, NI is the only region actively e-collecting the data as agreed by the National Lymphoedema Partnership.

Encompass and patient portal preparation

LNNI also continues to be an active stakeholder in the Encompass development project. In preparation for the new Encompass 'patient portal' resource, LNNI has worked with the current NIECR development team to produce a new ECR lymphoedema patient portal facility which is an interactive way to share information, goals and communication details with service users. This work was completed over the summer, and it is hoped that it will help facilitate an easier move to the Encompass system's patient portal.

3.0 All Ireland Lymphoedema guidelines

LNNI members were actively involved in the creation of the CREST Lymphoedema Management guideline (2008). There have been many technology and practice developments from 2008. Whilst the CREST document is still a valuable resource, it is recognised that it is timely to review the newest literature and present an updated document to support clinical practice. LNNI has joined in partnership with the HSE Lymphoedema project team to jointly fund and develop an All-Ireland Lymphoedema guideline.

During the 2020 spring and summer, the academic review work progressed and from early summer an evaluation process, supported by a large group of senior clinical staff and experienced service users, has rolled out. I would like to thank Carolyn in particular for joining the review group as a service user with many years' experience. It is planned to have the new document ready for wider consultation in April/May 2021, and publication in mid-summer 2021. This is a huge piece of work, and it has been fantastic working in an All-Ireland capacity with our HSE colleagues, and continuing to build our networks.

Components of this project are also to be sourced from recognised expert UK resources, such as the National Lymphoedema Partnership and the British Lymphology Society, plus international scientific bodies.

4.0 Cancer Strategy

The Cancer Strategy involvement was discussed at the LNNI December 2019 meeting, and despite a slow period over the first surge, this has re-focused and progressed rapidly from the late summer. LNNI has been very involved in drafting the 'Living Well' subgroup submissions, and in particular for lymphoedema.



LNNI also participated in the wider subgroup developments. In particular, LNNI supported the Prehabilitation section which we hope will improve pre-operative information provision, promote activity, good nutritional practice and supportive care, and help to 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. It is hoped that we will be able to target specific groups of people with a cancer diagnosis who are at high risk of developing lymphoedema, to focus a more person-centered and efficient screening and follow-up care programme.

The first three components of the strategy have been completed and the Strategy Management leads will meet later this week to progress cross subgroup analysis.

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. In the spring, we updated the '4 key messages' to become '5 key messages' with the help of our LNNI Board Service User review group. From the summer, we have been working to produce a new version of our '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 and senior Oncology Physiotherapists have been involved in this project alongside the LNNI team. It is currently with our LNNI Board Service User review group.

6.0 Education

Succession planning

At our December 2019 Board meeting, we had agreed to fund and support a regional lymphoedema certification course. This was necessary to support staff succession planning and ensure recruitment opportunities as the teams change. Each trust was offered two places and an additional two places were made available as per greatest need. The 4-module course commenced in February 2020, but we have been unable to provide the final three modules because of Covid 19. Our tutor has converted more of the theory into online teaching however until we are able to have agreement regarding a safe face-to-face teaching opportunity for the fourth and practical module, we have put the course on hold. It is hoped this will continue in the early spring once the vaccination programme for healthcare staff has been completed.

Specialist training

LNNI had agreed to support attendance at several international learning events over 2020 for our senior staff. Whilst the two International Lymphoedema Framework (ILF)



conferences are postponed until 2021, the teams were able to join the excellent virtual British Lymphology Society conference in October. LNNI has 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.

7.0 Paediatrics development

In late 2019, LNNI developed a regional care pathway for children with lymphoedema. As paediatric lymphoedema is relatively rare, discussions were opened with a consultant in the Royal Belfast Hospital for Sick Children (RBHSC), St Georges and the HSE to further develop an All-Ireland model. A proposal from RBHSC was drafted over the summer but progress is halted due to the impact of Covid 19.

8.0 Red Legs project

The Red Legs project was discussed at the December 2019 Board meeting. It has been difficult to progress, however education formats and clinical reasoning flowcharts were designed based upon the learning from the 2019 All Ireland Lymphoedema conference. Both have been shared with HSCB Pharmacy for publication in both pharmacy and primary care publications, once resumed.

In conjunction with this work, there has been discussion with HSCB Pharmacy about including additional labelling on cream/emollient products to promote good skin care and reduce risk of cellulitis.

9.0 Breast Cancer Services review

This work has not continued from February 2020 due to impact of Covid 19 and will be picked up when able. Lymphoedema services and potential for at risk screening has been added to surgical pathways.

Jane Rankin
LNNI Lead
2nd December 2020