



Lymphoedema Network Northern Ireland

NOTES OF BOARD MEETING HELD ON: 27th June 2022 AT: 10.00pm via Zoom

Present:

Attended **Apology received**

Ms Michelle Tennyson (MT) (Chair)

Ms Ceara Gallagher (CG)

Ms Jane Rankin

Dr Graeme Crawford, Primary Care

Ms Joan Hardy, DOH (JHy)

Ms Jill Hamilton (JH)

Ms Elaine McNeill (EMcN)

Jill Lorimer (JL)

Ms Lynne Whiteside

Mr Kevin Campbell

Mr & Mrs Greene, SHSCT PPI

Ms Carolyn McKeown, PPI NHSCT

SEHSCT PPI Vacant

Mr Ian McPherson, PPI BHSCT

Ms Kay Wilson, PPI BHSCT

Ms Claire Henderson, PPI WHSCT

SMT NHSCT- Rebecca Getty/Lynne McCartney

SMT WHSCT _ Vacant

SMT BHSCT – Ms Lisa Houlihan for Ms Debbie Wightman

SMT SHSCT – vacant

SMT SEHSCT – Ms Aveen McCraith

	ISSUE	CORE POINTS FROM DISCUSSION	ACTION
1.	Welcome and apologies	<p>MT welcomed:</p> <ul style="list-style-type: none"> - Ms Elaine McNeill representing SET in her new acting role - Mr and Mrs D Greene in their new role as SHSCT PPI representatives and representing carers of a child with lymphoedema <p>Apologies as noted above</p>	
2.	Previous minutes	<p>Minutes from Dec 21 agreed. JR to upload.</p>	JR



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3.	Matters arising	<p>3.1 New SET PPI rep to be appointed</p> <p>3.2 LNNI Children’s event: was due spring 21 but delayed with covid impact. Instead of a local 2022 event, the Board agreed to support 4 families to attend the national children’s event ‘Lymphaletics’ and to offer 4 grants of £250 to aid transport/accommodation in Sheffield. JR to progress.</p> <p>3.3 Draft children’s pathway project – delayed with covid and retirement of lead consultant. Will pick up again 3rd quarter 2022 (dependent upon covid levels and RBHSC resources)</p> <p>3.4 Bariatric surgical access concerns as SWAH service has not been established. There is still no action to re-establish plan for this service. MT & CG to raise as able.</p> <p>3.5 JR submitted LNNI domiciliary and Care Home paper to MT, CG and Mary Emerson in Jan 2022. MT and CG to pick up again re commissioning as on-going workforce issues with district nursing increase LNNI domiciliary contacts, and is a resource concern. MT looking to ensure regional consistency re access in all settings.</p> <ul style="list-style-type: none"> - JL to complete her report re recent domiciliary management project and share. - JH currently completing joint training with DN and finding that majority of the patients are bariatric, which has both equipment and H&S concerns. - LW has recently accessed waiting list temporary funding to pilot a project with a team member (nurse) working with DN to upskill. LW to share outcomes. <p>3.4 JR had approached the SET and WT in Jan 2022 re support to upgrade the U400 to SOZO. The WT felt unable to pick this up, but the SET had already completed purchase of two SOZO and will progress change of practice.</p> <p>JR has invited all LNNI leads and Oncology Physio leads to attend Aug 22 project team meeting with the new SOZO provider for the UK. A SOZO has been offered ‘on loan’, and this is being looked at by ST, WT and NT surgical physio teams, in conjunction with their breast surgery teams in the first instance. CG to work with JR re a potential end of year purchase of a SOZO device(s) from PHA monies.</p>	<p>EMcN</p> <p>JR</p> <p>JR</p> <p>MT & CG</p> <p>MT & CG</p> <p>JL JH</p> <p>LW</p> <p>Project team and oncology physio leads</p> <p>CG</p>
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4.	LNNI Board terms of Reference (ToR) and Annual Report	<p>4.1 ToR JR presented the Board ToR for review and update.</p> <p>MT, CG and JHy agreed to review the accountability section alongside the recent changes in strategic organisational structure.</p> <p>JR to make amendments and update membership/contacts.</p> <p>The Board to review the new changes by email communication prior to the Dec Board meeting.</p> <p>4.2 Annual Report JR presented the Annual report and thanked the project team, Board and all teams for their continued support over the year, and especially with the on-going impact of covid.</p> <p>Prior to ratification, MT requested that section 4.III be expanded and to include more data relating to access targets, and a summary of key messages as an appendix.</p> <p>Points relating to agenda items will be reported within their agenda section in the minutes.</p> <p>The Annual report will be re-circulated doe email review and agreed prior to the Dec Board meeting.</p>	<p>MT, CG and JHy</p> <p>JR</p> <p>Board</p> <p>JR</p> <p>Board</p>
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5.	Trust Lead Reports	<p>The five trust reports were presented.</p> <p>The Board congratulated the leads on developing new ways of working and on continued local developments and education alongside improvements with access to services.</p> <p>JL – reported that the temp band 6 nurse post is at recruitment for potential permanent recruitment, that the SQB project would re-start soon, and that 2 audits had been completed on impact of pandemic, and management of domiciliary workload. To share.</p> <p>EMcN – noted with concern the trust practice of booking new patient 12 weeks in advance and hence reducing availability of review slots. To discuss with line manager. Pilot with the ‘hands free’ volume assessment device is on going but has been hampered by both hardware and software challenges; this device is being compared to the traditional tape measurement volume measurement practice re feasibility in clinical setting and time resources. EMCN to continue to feedback re same.</p> <p>LW – waiting list funding has facilitated a ST pilot of a domiciliary nursing support worker role. LW to share report. Also noted the negative impact of covid with isolation, mental health and chronicity concerns noted in many patients. Team also providing on-going student placements.</p> <p>KC- reported improvements in access with temp staffing support, but still long waiting times. The temp staff have agreed reduced hours over summer which will impact again on access.</p> <p>WT – the waiting list is better and breaches should stop soon. A change in skill mix has facilitated a new band 4 post. Key concern is recent lack of clerical support, which impacts on clinical time; recruitment failed first time but is planned again for later in summer. This team is also taking student placements.</p>	<p>JL</p> <p>EMcN</p> <p>LW</p>
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6.	Clinical Practice planning	<p>6.1 Covid 19 impact and adaptations – Referral numbers dropped in 2020, however the latter half of 2021 and 2022 has seen an increase in numbers again:</p> <ul style="list-style-type: none"> • 2019 - 2105 • 2020 – 1402 • 2021 – 1983 • 2022 (5 months: Jan-May) 897 (Extrapolated for 12 months = 2153) <p>6.2 NMP progressing under PHA leadership. The ST and SET continue to be pilot sites and whilst paperwork is heavy, there has been a reported decrease in prescribing/transcribing errors.</p> <p>With the introduction of new nursing members to teams/new roles it has been recognised that there are other levels of NMP education taught at the UU, which would be suitable for the teams. The Board agreed to progress this option in Dec 21, and JR has furthered discussions with PSMs to reach an agreement to pilot and to bring back to Board for funding, and to progress with AHP Consultant Eamon Farrell (NMP Lead) regarding a hierarchy of need NMP model. CG to flag as a pressure to Denise Nixon, re potential surplus ECG funding for two places (£696pp) for the second semester 2022/23. The Board agreed to finance two places for pilot, if funding could not be resourced from the ECG.</p> <p>JR to progress with EF, and project team re nominees.</p> <p>6.3 As per item 3.2.</p> <p>6.4 NICE published their lipoedema liposuction document in March, which was not favorable. The April 22 lymphoedema liposuction paper was favorable as long as a team with expertise in managing lymphoedema completes patient selection, and in a specialist center; both have been shared with PHA and DOH EUR Policy group for inclusion in the EUR update in the autumn 22.</p> <p>6.5 The project team have almost completed a full review of all LNNI PIL to ensure best practice.</p>	<p>Project team</p> <p>CG</p> <p>JR and project team</p> <p>JR</p> <p>JR</p>
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7.	Progress Updates	<p>7.1 The new All-Ireland Lymphoedema Guideline is with formatter. The BLS, NLP and RQIA/GAIN and CAWT have endorsed the work. The new pathways created to support the document will facilitate future LNNI developments as per our 2018 plan. JR thanked CMcK for her continued work as the PPI (N.I.) rep on the steering group, and the project team for their continued input. JR is liaising with JHy and CAPHO re a potential Ministerial launch.</p> <p>7.2 Cancer Strategy and prehab/rehab working group LNNI continues to be part of the evolving cancer strategy workforce review. CG is co-chair of the prehab/rehab AHP/Pysch subgroup; she is currently liaising with the DOH cancer strategy leads and CAPHO regarding the AHP workforce review. The project team continue to support the role of prehab and screening/surveillance where possible; they will link with the new Prehab trust leads when in post.</p> <p>7.3 as per 6.4</p> <p>7.4 Encompass (and ECR patient portal) The full project team is actively working with the Encompass teams for the new regional electronic health record. The project team continue to work with the ECR patient portal team to develop this practice in order to prepare for Encompass. There will be a wide option of patient facing activities available from the Encompass portal.</p> <p>All formal assessment paperwork was reviewed again in early 2020 in preparation for this work.</p> <p>7.5 BSO are still suspending the Lymphdat SF2 launch due to resources but anticipate it will occur in next few months. The project team has discussed additions to this required by the on-going changes to the average patient population. JR will liaise with the IT consultant to add both a frailty measure and a risk assessment tool prior to launch. JR to add frailty tool to LNNI assessment format and circulate for use.</p>	<p>JR</p> <p>JR and JHy</p> <p>CG</p> <p>Project team</p> <p>JR</p>
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8.	Education (not covered in meeting due to time constraints)	<p>8.1 The Board had agreed to run another certification lymphoedema course in 22/23 to ensure succession planning within lymphoedema teams and oncology/palliative care. The CEC has agreed to be venue and dates have been circulated, with 10 out of 12 places already agreed.</p> <p>8.2 2022 BLS Annual conference – each trust has representation attending, and 1 oral presentation and 2 poster abstracts submitted.</p> <p>8.3 2022 Advanced masterclass (Klose Trg). The Board agreed in Dec 21 to run an event for specialist staff. JR worked with Klose trg (USA) to produce a successful Zoom masterclass with sessions from the USA and Germany including interactive case study discussions and problem solving.</p> <p>Places were also offered to the HSE to further cross border working. Feedback has been extremely positive, and there have been requests to consider a face-to-face session again next summer when Klose Trg are in Europe to provide the 3 week Foldi course.</p> <p>8.4 – covered in 7.1</p> <p>8.5 2022 Coban courses (introduction and advanced) JR has started planned with 3M to run a series of Coban classes in the late autumn. 3m educator still to confirm dates.</p>	<p>JR and LW</p> <p>Project team</p> <p>JR</p> <p>JR</p> <p>JR</p>
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9.	Communication	<p>9.1 The Network continues to work with:</p> <ul style="list-style-type: none"> - British Lymphology Society via the children and obesity subgroups - International Lymphoedema Framework via planning for 2023 conference - National Lymphoedema Partnership via committee and MDS subgroups <p>9.2 The Network is involved in 2 research projects via UU and Galway. The UU project has been delayed but will encourage positive behaviour change (around diet and well-being) via a wrist mounted 4-app device. LNNI will be encouraging participation to suitable service users, and the mainstay of the research will be completed by the UU. The Galway post-PhD work is developing a device to measure pressures when bandaging, and potentially under garments. Whilst initially envisaged as a teaching tool, this will eventually have a remote option for allowing data to be accessed from the patients' home. This is a longer-term project.</p> <p>9.3 JR submitted the LNNI DOH review in March 22 and awaits feedback.</p> <p>9.4 LNNI provided a speaker for the UU MSc Palliative care module</p> <p>9.5 At the Dec 21 Board meeting the topic of psychological support was raised. CH suggested peer support for new patients (or those who are finding lymphoedema and its life-long management challenging). JR and CH met and developed an action plan that includes piloting a peer support opportunity at the SHSCT's Healthy Leg 6 week class (once face-to-face classes are allowed again). The ST team have agreed to pilot and CH is developing an overview brief and a basic layout of a semi-structured presentation, which will link via Zoom. CH to continue pilot with JR and SHSCT team.</p>	CH, JR and SHSCT team
10.	AOB	10.1 LNNI have been working with the UU to submit a PhD proposal. The successful candidate will commence in Sept and JL will be the local adviser.	JL
11.	Dates for 2022 meeting	Next Board meeting is 9 th December 2022, 10.30am -12.30pm	Board