



Lymphoedema Network Northern Ireland

NOTES OF BOARD MEETING HELD ON: 13th December 2019 AT: 10.30pm IN: The Oak Room, Macmillan Support and Information Centre, Belfast City Hospital

Present:

Attended **Apology received**

Ms Michelle Tennyson (Chair)

(Vice Chair) vacant

Ms Jane Rankin

Dr Graeme Crawford

Ms Joan Hardy (JHy)

Ms Jill Hamilton (JH)

Ms Pippa McCabe

Jill Lorimer

Ms Lynne Whiteside

Ms Elaine Stowe

SHSCT PPI Vacant

Ms Carolyn McKeown

Ms Irvonae Glassey

Mr Ian McPherson

Ms Kay Wilson

Ms Claire Henderson

SMT NHSCT- Rebecca Getty/Lynne McCartney

SMT WHSCT – Paul Rafferty

SMT BHSCT – Ms Lisa Houlihan for Ms Debbie Wightman

SMT SHSCT – vacant

SMT SE HSCT – Margaret Moorehead

	ISSUE	CORE POINTS FROM DISCUSSION	ACTION
1.	Welcome and apologies	Apologies noted above. JR welcomed Joan Hardy who is known to some of the Board from her work with the 2007 Lymphoedema Implementation Team and 2008 CREST guidelines plus LNNI. JR also formally thanked Ms Jenny Keane (JK) for her support over the past years in her role as vice chair. Jenny has recently taken up the post of Chief AHP officer at the DOH.	
2.	Previous minutes	Minutes from Dec 18 agreed. The June 2019 meeting was cancelled as inquorate. JR to upload.	JR



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3.	Matters arising	<p>3.1 LW confirmed that she had approached the parent of a child with lymphoedema, and it was hoped they would become the new ST Service PPI rep. LW will confirm PPI name.</p> <p>PMcC will also find a new PPI rep.</p>	<p>LW</p> <p>PMcC</p>
	ISSUE	CORE POINTS FROM DISCUSSION	ACTION
4.	Chairman's remarks	<p>JK advised the Board that she had received a slippage list from LNNI project team to hold proactively for any available end of year monies. This was being looked at positively and leads should hear from the AHP leads soon; to action urgently.</p>	<p>Trust Leads</p>



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5.	<p>LNNI 10 Year review and 5 Year 2019-24 work plan And Trust Leads' reports</p>	<p>JR presented the 2019-24 updated work plan showing the activity in year 1 of the 5 year plan. Core to this was the development of the Health Needs Assessment (tabled later). All actions completed or on-going bar work to re-engage with UU re App 1 and bringing this into Apple format. JR to pick up in 20-21.</p> <p>JK had added this to the PHA work plan in June 19.</p> <p>The Board congratulated each of the trust leads after they had presented their work on progress regarding new models of care and new partnerships.</p> <p>Overall, referral numbers continue to increase year on year. Four out of the five trusts are currently breaching.</p> <p>New referrals:</p> <ul style="list-style-type: none"> • 2017 – 1636 • 2018 – 1871 • 2019 - 2105 	JR
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6.	Clinical Practice Update	<p>a. 2018 LNNI children’s event – 2019/20 plan</p> <ol style="list-style-type: none"> 1. Cancelled due to low numbers available this year. 2. Board has agreed to do this every 12-18 months so plan again for spring 2021. <p>b. Palliative care AHP workforce</p> <ol style="list-style-type: none"> 1. Current regional P Care workforce review taking place. Disparity across trusts re who manages palliative lymphoedema i.e. some SPC teams do it and in others it is the LO teams. 2. LNNI is involved in the review, and lymphoedema should be built into the physio workforce modelling as it was included in the 2018 AHP SPC evidence review and 2019 workforce review. SPC Physios should in future cover palliative lymphoedema for all trusts. We will need to continue to keep this on the agenda with the SPC AHP Forum/Corinna’s replacement. <p>c. Pharmacy – JR met (April 19) with PHA contact Andrea Linton to discuss local issues and be involved in the new pharmacy review/NMP. (Nov 19) Preparing an outline Business Case to implement an ECR solution to producing HS21 scripts at Interface areas.</p> <p>d. Formalising intra-trust education(at risk) programme: trusts to have a formal calendar of education events plus info section on trust intranet/HUB -> as per 2019-24 plan</p> <p>e. Garment supplies (local and UK work)</p> <ol style="list-style-type: none"> 1. Local: Have picked up recent local issues regarding patients being asked to part-pay for garments supplied from community pharmacies as the BSO pay-back amount does not cover full cost. Jane has linked with the Community Pharmacy NI CEO regarding how to begin to solve. 2. National: Jane continues to sit on the national compression review group (Multi-prof). This aims to reconfigure how garments would have traditionally been categorised by “class” and change this into more logical and correct “pressure” banding. Aims to address improved prescribing habits alongside a simplified GP tool. 3. All-Ireland: Jane is continuing to link with HSE re their plans to limit scope of options. 	<p>JR</p> <p>JR</p> <p>JR</p> <p>Trust Leads</p> <p>JR</p>
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7.	Progress Updates	<p>a. LNNI Health Needs Assessment</p> <p>i. The ILF project published its population results from the international study (May 19). Jane drafted the local health needs assessment (August-Sept) and trust leads reviewed Oct. Michelle to add foreword in Nov/Dec. The Board ratified the report.</p> <p>b. Capacity and demand exercise – NT</p> <p>i. Michelle to meet again with Linus to discuss outcome of LNNI spreadsheet (2017), and later with Physio SMs.</p> <p>b. Surgery - PHA paper and LNNI information leaflet Drafted in partnership with PHA Public Health Consultants (July 19) in conjunction with LNNI patient information leaflet. Paper discussed at SCCG 11th Dec 19. Eamon Farrell (AHP consultant) in attendance. JH also attends SCCG and will liaise with JR/MT as required to progress.</p> <p>d. Paediatrics</p> <p>i. A project team created a draft paediatric pathway in conjunction with the RBHSC, regional paediatric physios, VA (RVH) and RBHSC. To progress.</p> <p>ii. The project team would like to explore the option of requesting a yearly/18 month clinic with a clinician from St Georges, London for paediatric review. The Board agreed to progress. Video-conferencing might be an option.</p> <p>e. Bariatric lobbying</p> <p>i. Continued lobbying re case of need, with particular need for role of psychology and dietetics for the non-cancer population.</p> <p>ii. JR presented at the NICON conf (May 19) and used lymphoedema as a case study to highlight multi-morbidity (including bariatric impact).</p> <p>iii. JR met with PHA contact from DOH bariatric group re new SWAH service (May 19; update Oct 19) – welcomed new bariatric service, especially the potential for access to Tier 3 services i.e. psychology/ dietetics if not suitable for surgery. LNNI will continue as a stakeholder, and Trust Leads alerted to the likely initial population or surgical list for when recruitment commences. Only 100 cases per year initially. Delayed to after election.</p>	<p>MT</p> <p>MT</p> <p>JHy</p> <p>Project Team</p> <p>JR</p> <p>JR</p>
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		<p>f. Vascular update/pathway</p> <ul style="list-style-type: none"> i. JR presented to the regional vascular group in March 19 re the expanding demand for simple oedema management. Agreement that LNNI will be involved in the new vascular pathway draft. Request made to have a seat with the group in future (to be discussed in June 19- no further feedback). Board agreed to follow up with potential for a MP pathway workshop. <p>g. Lymphdat development update /Encompass</p> <ul style="list-style-type: none"> i. Lymphdat short form (SF) launched (March 19). All trusts should be recording on the original or SF versions as per new work plan. ii. The LNNI Board should agree how we can share our data reports: who/where for the 2019-24 development. JR to discuss with MT. iii. JR continuing to meet with Encompass team re future planning. Encompass team impressed with Lymphdat and encouraging continued data collections whilst procurement continues for their preferred system. Initial thoughts would be that Lymphdat might be able to link with new system. iv. Lymphdat ICT contact is linking with SHSCT PARIS contact to investigate data population with the new system (unsuitable for the older BHSCT systems). v. Project team will need to review assessment formats again in early 2020 in preparation for formatting of Encompass. Board agreed JR to run a half-day assessment workshop. vi. To note, there is a concern regarding access to hand held devices. <p>h. E-health: App projects & text reminder</p> <ul style="list-style-type: none"> i. Both Apps now complete and details of how to access on LNNI website. Working towards App2 being on NHS App store. We still need to develop an Apple version of App1. ii. The BT launched a text reminder system; this has significantly reduced DNAs. Both Apps and test reminder were included in a poster selected for the ILF (won first prize and a free place at ILF conf 2020!) iii. GP TV project – JR in discussions with NLP/Legs Matter 	<p>JR</p> <p>Trust Leads</p> <p>JR/MT</p> <p>JR</p> <p>AMcC/JR/LW</p> <p>JR</p> <p>JR</p> <p>JR</p> <p>JR</p>
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		<ul style="list-style-type: none"> vi. Lifetime Achievement Award by the British Lymphology Society for JR in Oct 19 vii. International Lymphoedema Framework: JR continuing to work with this group including part of the outcome measure project. viii. National Lymphoedema Partnership: JR continuing with this great partnership including the launch of the national commissioning guidelines (March 19) ix. Legs Matter campaign (June 20) plans x. Action Cancer MLD service Project team worked with charity to agree a self-referral service for patients who wish to have more MLD (Aug 19) 	Team Leads
8.	A.O.B.	<ul style="list-style-type: none"> i. Slippage money update and update re procurement ii. Regional Cancer Strategy – new item for work plan (Sept 19). JR sitting on Living Well sub group iii. New item for work plan re PHA/HSCB breast cancer review (Dec 19). JR sitting on group. iv. IMcP suggested creating a clothes bank for any old or unused compression garments that could be given to Third World. JR to table for progress at Project team meeting. v. JR to ask about further slippage re grant for families re 2020 Lymphaletics v. To add in-patient need to 5 year plan 	<p>All leads JR</p> <p>JR</p> <p>JR JR JR</p>
9.	Date of next meeting	<ul style="list-style-type: none"> - 19th June 2020 - 11th December 2020 	LNNI Board