



Lymphoedema Network Northern Ireland

NOTES OF BOARD MEETING HELD ON: 31st May 2016 AT: 10.30am IN: The Oak room, Macmillan Support and Information Centre, Belfast City Hospital

Present:

Attended **Apology received**

Ms Jenny Keane (Chair)

Ms Jane Rankin

Dr Graeme Crawford

Mr Joe Magee

Ms Jill Hamilton

Ms Pippa McCabe

Ms Lynne Whiteside

Ms Gillian McCollum/Jill Lorimer

Ms Elaine Stowe

Ms Tara Murphy

Ms Carolyn McKeown

Ms Irvonae Glassey

Ms Peggy Moore/ Mr Ian McPherson

Ms Kay Wilson

SMT NHSCCT- Rebecca Getty

SMT WHSCT – Paul Rafferty

SMT BHSCT – Gillian Traub

SMT S HSCT – vacant

SMT SE HSCT – Margaret Moorehead

| | ISSUE | CORE POINTS FROM DISCUSSION | ACTION |
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| 1. | | JR welcomed Ms Jenny Keane as acting chair whilst discussions continue re permanent chair. Apologies noted above. | |
| 2. | Previous minutes | Minutes from December 2015 agreed. JR to upload. | JR |
| 3. | Matters arising | All items covered by agenda. | |



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| 4. | Chairman's remarks | On-going challenge regarding the changing commissioning perspective. JK and JR to meet with Michelle Tennyson to agree a formal chair, and to look at ways to further LNNI via the PHA. | JK and JR |
| 5. | Trust leads reports | <p>The teams are well recruited - much improved from 2015/16. Key issues related to the increasing number of non-lymphoedema referrals including lipoedema. Some trusts seem to have a recent increase in domiciliary referrals.</p> <p>Also mentioned are the prescribing issues, which have improved on the whole, but are still causing basic issues. JH to send her prescribing audit to JK.</p> <p>The NHSCT is at capacity and has not received any additional funding from set-up; it is no longer able to meet waiting time targets. ES is working with her service manager using the LNNI capacity/demand template to address the demands. The other teams are attempting to support referrals in bordering areas.</p> <p>The team leads were thanked and congratulated on maintaining leadership and demonstrating inspiration and energy in all aspects of their role. The initiative looking at areas of low referral e.g. Chinese population, and developing relationships with same, was raised of particular interest to the PHA.</p> | JH |
| 6. | Annual Report | JR reviewed the document with the Board. As there were no further questions, the report was ratified. JR to upload to website. | JR |



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| 7. | Clinical Practice discussion | <p>7.1 LTC model is very much supported by the Donaldson consultation paper. Two hydrotherapy programme are in progress to aid self-management; 1 each in the Set and BT. The ST is also about to pilot a 2 week self-management programme. The leads will feedback re potential regional roll out.</p> <p>7.2 JR has been leading a regional paper to support the development of palliative care. A paper has been accepted by the regional specialist team led by Corrina Grimes. New palliative care posts are to be interviewed for the WT in the near future. JH is to liaise regarding partnership working.</p> <p>7.3 JR has been driving this regional report regarding use of Doppler for lymphoedema. This is in final draft and will be launched at the TV Forum in August. JR has started a national group to also look at practice and will bring the paper to them once launched regionally. This group will then progress to look at wider vascular issues and look at a national approach. JR and the Lead TVN continuing to try to raise support in the BT re pilot Well Leg clinic. There has been a block regarding new projects from start of year.</p> <p>7.4 On average we now have 4 patients per year applying for liposuction consideration. The project team will continue to monitor. This is still not a sufficient number to consider a staffing bid for local services.</p> <p>7.5 LNNI has continued to support the care of patients with lipoedema, including their study day. This is in spite of no formal funding but in recognition of lack of other services for them. One of the hydrotherapy projects is focusing on increasing activity programmes access for this group.</p> <p>7.6 The PhysioTouch pilot in 2015 was very successful. The SET and ST were able to access end of year monies to purchase a machine each. JM is to liaise with JK re potentially progressing wider access. JR to liaise with the company re purchasing cost, and with JM re business case development.</p> <p>7.7 Paediatric work: on-going up-skilling of local staff with a study day in April 16. All babies and children facilitated to attend the regional genetics clinic for diagnosis and potentially family history plotting. ES and JH are now members of the national group. Staff are encouraging those with primary lymphoedema to also consider genetic assessment.</p> <p>7.8 The new discharge policy is working very well; to date re-referrals have been appropriate in 90% of cases. Feedback has been positive from both service users and patients.</p> | <p>JL/GMcC, PMcC and LW</p> <p>JR JH</p> <p>JR</p> <p>Project team</p> <p>Project team</p> <p>JM, JK and JR</p> <p>Project team</p> |
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| | | <p>7.9 JR is continuing to work with the PHA regarding the pharmacy education package for both patients and pharmacists. This has now been adapted for GPs. This is due to be launched in late June 16.</p> <p>7.10 AHP Prescribing: JH and a member of the ST team have passed the full prescribing course, however there remain issues regarding the practical aspect of this role. JK, as the AHP commissioners leading this work, is continuing to develop the practice.</p> <p>JR is also working with the PHA to establish the use of product codes to aid correct prescribing (from GP). Several companies have been shown to have this prescribing option, and this has been shared with all teams. The outcome of this work has been shared nationally and JR is working with the manufacturers to try to expand this for all use.</p> <p>JR liaising with Wales re their learning and linking with regional procurement re new regional review of compression hosiery.</p> <p>JK has proposed a GAIN audit to build upon the initial prescribing audit by JH to identify issues and also highlight the cost/waste associated with incorrect ordering. JK and JR to progress.</p> <p>7.11 The teams have identified the new role of a band 4 assistant. JR has convened a national group to look at job descriptions and competencies which could be used for local roll out when funding is available.</p> <p>7.12 The team has developed an education package for use with carers. This has several resources including a self-assessment quiz. To be rolled out regionally.</p> <p>7.13 a new risk assessment has been created to supplement the basic assessment – as required.</p> | <p>JR</p> <p>JK and project team</p> <p>JR</p> <p>JR</p> <p>JR and JK</p> <p>JR</p> <p>Team Leads</p> <p>Team Leads</p> |
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| 8. | Progress updates | <p>8.1 The team had one complex clinic in the past 18 months (Oct 15) to review vascular cases with Ms Reid. All surgical opinions re liposuction now going via GP/consultant. The project team will continue to monitor this and plan according to need.</p> <p>8.2. The project team has developed an e-outcome measure section for Lymphdat which is now live. A new volume calculator has also been developed to aid assessment and is embedded in the data set too.</p> | Project team |
| 9. | <p>Additional work streams</p> <p>9.1 Education:</p> <p>9.2 Communication:</p> | <p>9.1.1 General: focusing on CEC awareness day and the new Neonatal Network</p> <p>9.1.2 Undergraduate trg – all as planned</p> <p>9.1.3 Specialist: Skin Masterclass (Nov 15), Paediatrics/lipoedema (April 16) Foldi update (June 16) and Generalist up date for those trained but not part of lymphoedema teams (Oct 16). For band 3s: 2 x study days re anatomy and physiology, and compression (Oct 15 and May 16).</p> <p>9.1.4 Future specialist trg: psychology support. To discuss next band 3 trg in line with the national competencies being developed.</p> <p>9.1.5 PPI: awareness visit to Chinese Welfare Centre (March 16) to be followed up with Muslim Centre visit in autumn.</p> <p>9.2.1 Continuing to build relationships with BLS, the new National Lymphoedema Partnership, the International Lymphoedema Framework and the Irish Framework.</p> <p>9.2.2 All teams now using ECR and CCG.</p> <p>9.2.3 New Easy read self-care leaflet in development with support from 2 groups with patients who have learning disability. The groups have also agreed to look at the 4 key messages postcard too.</p> <p>9.2.4 PMcC and JR to progress the App potential.</p> <p>9.2.5 2 abstracts have been submitted to BLS (JH and PMcC)</p> <p>9.2.6 The regional participation in Lymphoedema Awareness week (March 16) was highlighted in the BLS newsletter – all teams utilised the opportunity to highlight lymphoedema to both potential sufferers and also HCPs.</p> <p>9.2.7 The work is nearly completed regarding the LNNI website update; hopefully launching in July 16.</p> | <p>Project team</p> <p>JR</p> <p>JR and GMcC</p> <p>JR</p> <p>JR and PMcC</p> |



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| 9 | AOB | 10.1 LNNI have been asked to be formal advisors to a New Zealand lymphoedema strategic development plan 10.2 PMcC mentioned that a recent patient attending for liposuction had been prescribed a garment that would not normally to used regionally due to expense and the availability of other suitable garments. JR to liaise with the surgeon. | Project team JR |
| 10 | Date of next meeting | 6 th December 2016 | For all diaries |