

## **Worcestershire Health Care Trust: Lymphoedema Service Review, March 2018**

### **British Lymphology Society Final Report**

#### **Purpose of Report**

This report has been prepared to inform NHS Redditch and Bromsgrove Clinical Commissioning Group, NHS South Worcestershire Clinical Commissioning Group and NHS Wyre Forest Clinical Commissioning Group, referred to hereon in as Worcestershire Clinical Commissioning Groups (WCCG) of the findings of an independent review of the Lymphoedema Service. WCCG are asked to note the contents of the report and facilitate Worcestershire Health and Care NHS Trust (WHCT) to formulate an action plan based on the recommendations.

#### **Background**

Following concerns raised by a patient receiving treatment from the Worcester Health and Care NHS Trust (WHCT) Lymphoedema Service, the British Lymphology Society was asked to undertake an independent review of the service. This unusual step was taken at the request of WCCG in support of the patient's request, as the patient had questioned the ability of WHCT to undertake an impartial internal review that would be adequately informed by expert opinion.

The British Lymphology Society (BLS) is a registered membership charity pursuing a mission to "*actively promote professional standards and the study, understanding and treatment of lymphoedema / chronic oedema*". Consequently, a review panel comprising the Society Chair and two other Trustees was convened and the scope of the review was agreed by the Accountable Officer of WCCG, the BLS and the patient. All three panel members are registered nurses currently engaged in specialist lymphoedema clinical practice with experience of nurse led community lymphoedema services, service development and undertaking reviews of practice.

#### **Purpose and Scope of the Review**

The aim of the review was to identify and make recommendations on ways in which the service may effect positive change for the benefit of all patients. It was agreed that the review would be informed by the examination of care provided to a small sample of patients, including the individual who had raised concerns, to reflect the patient profile of the service, but would not make judgements on the care of any specific patient. Aspects of good practice would be highlighted in addition to aspects requiring improvement, but no judgements would be made in relation to specific clinical cases.

Worcestershire CCGs agreed to inform the public, via a report published on the public facing webpages of the CCGs by 19<sup>th</sup> July 2018, that a review has been undertaken by the British Lymphology Society, at the request of the CCGs of Worcestershire. The report will share key points highlighted by the report of the panel and will include plans that the CCGs and WHCT agree to take to respond to learning points identified.

### **Review Process**

Key questions were identified in advance to provide a framework for the review and enable a full understanding of the service profile and context. A range of documents and records were reviewed in advance of a site visit on 13-14 March 2018. The site visit involved interviews with all relevant members of clinical, administration and managerial staff, a sample of patients, including the individual raising concerns and an examination of additional documents and records.

### **Key Questions**

The following questions were identified to inform on: Referral, Assessment, Treatment, Follow-up, Service Review and Enhancement, Adequacy of Staff, Resources and Management Support, and Patient-centredness.

1. Is appropriate documentation used effectively?
2. Are treatment decisions adequately documented, based on individual clinical need?
3. Is the outcome of treatment evaluated and adequately documented?
4. Is there evidence of audit activity?
5. Is there evidence of service users and other stakeholder feedback?
6. Have any complaints been received?
7. How has the service responded to feedback or complaints?
8. Is there evidence of organisational / practitioner learning from feedback and reviews?
9. Are there sufficient staff with appropriate qualifications, skill and experience to deliver care?
10. Is there evidence of staff maintaining currency of knowledge and skill?
11. Are facilities adequate to deliver the service?
12. Are appropriate garments available to meet individual patient needs?
13. What is the process for provision of garments?
14. Is there evidence of management support and reporting processes?
15. What processes are in place to manage patients whose requirements extend beyond the scope of practice of service staff?
16. Is there evidence of service user engagement?
17. Is there evidence of supported self-care?
18. Is there evidence of appropriate referrals to other services and follow-up?

In addition, the service was also invited to submit a brief reflective report on good practice, innovation and service improvements implemented or planned improvements.

**Points of external reference for the examination of the service included:**

- Nursing & Midwifery Council in 'The Code' (2015)
- British Lymphology Society Members Code of Conduct
- British Lymphology Society Standards of Practice for Lymphoedema Services
- Lymphoedema Framework Best Practice for the Management of Lymphoedema where relevant. Although sections of this document are out of date in respect of specific aspects of clinic practice and have been superseded by more recent published research, which will be used as a reference as appropriate, the basic 'Standards of Care' remain relevant.

### **Overview of Review**

WHCT management engaged very positively with the review and endeavoured to ensure the Review Panel had access to all the evidence required. There were limitations in relation to the range of clinical evidence reviewed on account of confidentiality issues. Although it was regrettable that patient concerns had focused attention on the lymphoedema service, the review panel were greatly encouraged by the extent to which senior management recognised inadequacies, and their commitment to address these. Several recommendations have been made in relation to strategic management of the service and clinical practice and service delivery.

### **Commendations and Positive Feedback**

- A. The Trust clearly demonstrated a willingness to learn from the review and their own reflection on the service and had already taken several steps towards improving the situation.
- B. One additional whole time equivalent (WTE) clinical specialist is being recruited. Although this will not bring the staff complement to what it was in 2009, it will support service delivery while the needs are evaluated more thoroughly.
- C. The need for leadership development and support is beginning to be addressed and clinical supervision is being introduced.
- D. The introduction of an Integrated Community Leader is considered a positive step.
- E. New referral screening and triage documentation is commended.
- F. Facilities at Pershore Hospital are very good.
- G. The service has one nurse prescriber with a second in training, supporting a garment provision service with no restrictions and therefore ensuring individual patient needs can be met. Garment review appointments further support good practice in this aspect.
- H. There is dedicated administrative support for the service.
- I. The use of a message book supports effective communication between the various team members and seems to be maintained well.

### Historical Context and Contractual / Service Management Issues

The historical context of the service was considered to have had a significant impact on how it currently operates. The service had been established in 2009 as part of the palliative care service with five specialist posts pump-primed by Macmillan Cancer Support. Subsequently, as charitable funding came to an end and various changes in NHS structures and management were implemented within a context of national funding challenges, priorities of the Trust and WCCG were focused elsewhere. Despite so many changes, including 5 line managers in 3 years and a shrinking lymphoedema team, there had been no review of the Service Specification, expectations or monitoring of what the Lymphoedema Service delivered, whether the skill mix was appropriate and no leadership development. No minimum data set is maintained. It was fully acknowledged by senior staff that little attention had been afforded the lymphoedema service.

### Key recommendations for strategic management of the service

1. *Develop a robust business plan* based on an understanding of local prevalence / need for the lymphoedema service **as a matter of urgency** as this will underpin all other actions. It will enable a clear understanding of the population needs and costs of delivery, determine staffing and skill mix requirements. The Trust should consider guidance and templates already in existence to support this activity, e.g. the Healthy London Partnership document "Lymphoedema services for adults living with and beyond cancer: A template business case for commissioners, or the British Lymphology Society Tariff document. Consideration of broadening the discipline mix in the team, to include physiotherapy, or a Band 4 support worker, is also encouraged. Also consider ways of integrating / collaborating with other teams. In the meantime, the planned Band 7 post should be appointed as soon as possible. It is suggested that consideration be given to rationalising the remote clinic services for effective staff deployment.
2. *Update the service specification to reflect population needs. This will be the responsibility of WCCG.* Examination of other service specification documents, e.g. the Anglia Cancer Network Service Specification for Lymphoedema is encouraged. This will set clear expectations for the team and set criteria for ongoing evaluation of the effectiveness of the service and should be reviewed by management at regular intervals.
3. *Develop meaningful Key Performance Indicators* for the service and team. Initially these may be modest but should set appropriately challenging goals that reflect the agreed activity.
4. *Initiate appropriate monitoring and reporting mechanisms* to evaluate effectiveness of the services, the need for development and resources and ensure management continues to be engaged, have clear oversight of the service and its needs and the lymphoedema team and the organisation are working towards the same goals. Mechanisms are required to ensure that meaningful two-way supportive communication is maintained. Engagement in some team meetings may foster positive engagement and provide support and learning opportunities for the team leader.

5. *Implement an effective staff development and training plan with clear pathways* for development posts and a competency framework, e.g. a modified version of the local Chronic Oedema Competency Tool. Leadership development within the service, mentorship and support is crucial. We recommend the new Team Leader post be an interim /development role for at least 6 months and then reviewed to enable development of skills and confidence and the vacant post has been filled. Clinical specialists are recommended to attend updates for the specialty 2-3 yearly. In addition to updating clinical skills, such updates provide a forum for discussion amongst experienced clinicians who are managing services. As an example, a recent Casley-Smith update in Glasgow focused on supporting self-management, challenging clinicians on the extent to which their practices and communication were patient-centred, evaluating outcomes and raised many issues and tips on formal communication with GPs and patients. Consider formalising clinical supervision in respect of clinical decision-making, to complement the current arrangement in relation to management.
6. *Identify a clear management structure for clinical and administrative staff.* A clear job description for the team leader role is required urgently. We suggest that a key component of this role is to gather data, understand trends within and affecting the service and present these effectively. The job descriptions / expectations of all team members should be reviewed to support effective team working.
7. *Review the administrator role and support* in exploring options for developing more efficient ways of working and using the new electronic systems, including electronic referrals, generic email, electronic letter templates, data collection.
8. *Enable and support the development of documentation* to meet the needs of the service and enable extraction of meaningful data by embedding a Minimum Data Set within the e-Care Notes. Processes for periodic audit of the clarity, adequacy and comprehensiveness of the assessment and treatment records should be integrated.
9. *Ensure all relevant risk assessments are undertaken*, e.g. moving and handling and that there are processes in place to undertake a meaningful patient survey on a regular basis, e.g. annually.
10. *Identify expectations for waiting lists within a practitioner-led service* and make this publicly accessible.

#### **Key recommendations for clinical practice and service delivery**

11. *Develop Standard Operating Procedures (SOPs)* and specific treatment pathways for specific diagnostic/patient groups to guide practice, indicating criteria for Decongestive Lymphatic Therapy (DLT). Ensure deviation from the 'prescribed' pathway is recorded with clear rationale for this.
12. *Develop clear patient pathways* from referral to discharge with clear discharge criteria and easy re-referral/self-referral should any changes in condition warrant reassessment to lessen anxiety about discharge. Update referral criteria and link with KPIs.
13. *Adopt an approach that strengthens patient empowerment* and supports self-care from the outset and fosters an expectation of discharge at a future point in time.
14. *Check currency of clinic generated patient information leaflets* and update as required.



15. *Develop a leaflet for patients about the service.*
16. *Ensure the electronic notes system is used effectively and generates a MDS.* We suggest an exploration of how others use documentation, e.g. a diagnostic and treatment summary page that remains at the front of the notes. This recommendation incorporates a number of specific recommendations in relation to documentation including the recording of:
  - a. A clear lymphoedema diagnosis with staging, key causes and contributory factors (at point of assessment – not from referral form) with an option to add key findings from subsequent investigations, e.g. the Glasgow Patient Assessment Form;
  - b. Comprehensive assessment;
  - c. Clear treatment decisions and plan;
  - d. If oedema is bilateral, severity should be noted as a subjective judgement. Subsequent changes in volume should be evaluated by comparing measurements in the same limb.
  - e. Evaluation of effectiveness of the treatment;
  - f. Patient perspective, priorities and impact of the condition / treatment;
  - g. Justification for modification to treatment plan or SOPs;
  - h. Review functional assessment and explore a more effective way of assessing and recording this;
  - i. Consider a patient self-report form issued prior to appointment.
17. *Identify a minimum data set* to be embedded within the e-Care Notes to facilitate reporting and identification of trends to inform future service development and enable benchmarking with other services.
18. *Initiate processes for audit* of clarity, adequacy and comprehensiveness of care documentation. Consider annual patient survey specific on the service.
19. *Communicate with the patient's GP* after every assessment / review / episode of treatment, indicating the response to treatment and any changes that have occurred. Care is required in the use of language in such communication.
20. *Communicate formally with patients* after clinic appointments – consider copying any GP letters to them. Ensure patients are informed of any actions in response to feedback.
21. *Consider changing appointment slots* to allow 1.5 hours for new patients and for those having DLT but reducing review appointments to 45 minutes. This should enable completion of notes before seeing other patients.
22. *Explore potential for integration / collaboration* with the Tissue Viability Service, specifically considering the use /modification of the Chronic Oedema Pathway. Physiotherapy service collaboration / integration may also be a very positive step.
23. *Develop effectiveness of team meetings* with clear purpose to engage and value team members, instil a feeling of positivity, team ownership and inclusion in future planning and learning from feedback.
24. *Work as a team and with management* to develop appropriate KPIs and an action plan to meet these, reporting on this annually.

Question	Findings
1. Is appropriate documentation used effectively?	<p>A process is underway to transfer from paper to electronic notes (e-Care Notes). There appear to be lots of gaps in paper notes and a limited review of electronic notes made it difficult to ascertain how consistently key details were recorded. Although the e-Care Notes were more comprehensive there are some key aspects of clinical assessment that need to be more explicitly and clearly documented. The recorded diagnosis, which is what is seen on opening the notes seemed to rely on the information given by the referrer and not further clarified at that point. The extent and staging of the lymphoedema could be documented more clearly.</p> <p>The patient perspective and the impact of the condition on them could be more effectively recorded.</p> <p>The service has no discharge criteria. Functional assessment reporting is not particularly informative. Although activity reports are available, there is little to inform on the patient profile of the service and no minimum data set.</p> <p>Referral criteria exist but should be updated.</p> <p>There is no minimum data set generated to inform development.</p>
<p><b>Recommendations 8,14,15,16,17</b></p> <p><b>Advantage should be taken of the transition to e-Care Notes to ensure the documentation is fit for purpose for the lymphoedema service.</b></p>	
2. Are treatment decisions adequately documented, based on individual clinical need?	<p>Some important findings were ‘buried’ within the written text, so not always easy to find and follow decision-making. There seemed to be reliance on the referral request to identify the diagnosis, rather than a comprehensive assessment by the lymphoedema clinical specialist. It wasn’t always explicit why certain treatments were instituted or modified from standard practice. However, on questioning on a very limited number of specific cases, staff were able to explain appropriate rationale for treatment decisions.</p>
<p><b>Recommendation 8,12,16,18</b></p> <p><b>Consider a 360 review of clinical decision-making.</b></p>	
3. Is the outcome of treatment evaluated and adequately documented?	<p>A clear evaluation of the effectiveness of the initial treatment plan or reasons for changing treatment was not always adequately recorded.</p>
<p><b>Recommendations 16,18</b></p>	
4. Is there evidence of audit activity?	<p>Only as part of the Trust general audit exercises, nothing specific to the lymphoedema service.</p>

<b>Recommendations 8,18</b>	
5. Is there evidence of service users and other stakeholder feedback?	Yes, through the Friends and Family Test but nothing specific to the lymphotoedema service.
<b>Recommendations 9,16,18</b>	
6. Have any complaints been received?	Patient experience is mainly highly positive. Delays in receipt of garments is the main issue identified in feedback. The only complaint received was for the issue that resulted in the review.
7. How has the service responded to feedback or complaints?	Not clear if there has been specific feedback to patients about the issues raised about garments.
<b>Recommendation 20</b>	
8. Is there evidence of organisational / practitioner learning from feedback and reviews?	Organisational learning is clear in response to the concerns expressed by patient that resulted in the review. Prior to this there was little effective engagement between the service and management. There is no clear documented response on learning from the team. The new practice of team meetings has the potential to enable learning and documentation of this.
<b>Recommendation 23</b>	
9. Are there sufficient staff with appropriate qualifications, skill and experience to deliver care?	Not at present. There is only one qualified specialist, but another is about to be appointed. Robust information on the population and service need is required to ascertain what is required, but additional input may be required. There is a lack of leadership and management skills that has thwarted the development of the service strategically and functionally. Steps are being taken to address this but it will require scrutiny of skills requirements and potential, support, mentoring and monitoring.
<b>Recommendations 1,2,4,5,6,7,21</b>	
10. Is there evidence of staff maintaining currency of knowledge and skill?	Yes, although some development has been delayed for reasons outside the control of the service.



<b>Recommendation 5</b>	
11. Are facilities adequate to deliver the service?	Facilities at Pershore Hospital are very good. There was no opportunity to see facilities at outlying clinics.
12. Are appropriate garments available to meet individual patient needs?	There appears to be no restrictions on the range of garments that a patient may be prescribed.
13. What is the process for provision of garments?	There is one nurse prescriber, with another in training. A review appointment is made to check the garment provided is a good fit and the patient is able to don and doff it. Patient complaints highlight some issues with delays in receiving garments. However, this is a national problem.
14. Is there evidence of management support and reporting processes?	Previously management had little engagement with the service but steps are being taken to address this with a new structure and the appointment on an Integrated Community Lead.
<b>Recommendations 1,3,4,23,24</b>	
15. What processes are in place to manage patients whose requirements extend beyond the scope of practice of service staff?	There is evidence that referrals are made to a specialist centre if the case is particularly complex. Clear criteria for referral may be helpful.
16. Is there evidence of service user engagement?	Limited – feedback through the Friends and Family Test but nothing specific to the lymphoedema service.

<b>Recommendations 18,20</b>	
17. Is there evidence of supported self-care?	There is evidence of information provision, however, some leaflets although very good, require to be updated and have version control and review dates visible. Patients were not keen to consider discharge from the service.
<b>Recommendations 12,13,14,15</b>	
18. Is there evidence of appropriate referrals to other services and follow-up?	There is evidence that referrals are made to a specialist centre if the case is particularly complex. There is evidence of good communication between the service and specialist centre but also evidence of gaps in communication. No evidence seen in respect of referrals or feedback from local services, e.g. weight management, psychological support. There appears to be a historical difficulty in collaborating with the tissue viability service in the community.
<b>Recommendations 7,19,22</b>	
<p>Copying correspondence to the patient may avoid some misunderstandings.</p> <p>The local Chronic Oedema Pathway is due for review in May 2018, which may provide an opportunity to engage with this service.</p> <p>Electronic referrals might be more efficient.</p>	

British Lymphology Review Team

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