All Wales Lymphoedema Service and Community Pharmacy Wales Collaborative Project Terms of Reference (ToR)

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Owner:
All Wales Lymphoedema Network Group & All Wales Medicines Management Board

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Revision History

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<th>Changes marked</th>
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Purpose and Summary of Document:

1. To outline the approach, objectives and timescales for the appraisal and development of a Pharmacy service to support the needs and requirements of Lymphoedema patients in NHS Wales. The key outcomes of this work will focus on the reduction of harm, variation and waste in the prescribing process for Lymphoedema patients.

2. Seek endorsement and agreement from the Community Pharmacy Wales Board for this proposal.
1 Background

1.1 Lymphoedema is a chronic swelling due to lymphatic system failure. It can occur from a congenitally determined lymphatic abnormality or from lymphatic damage by inflammation, infection, trauma, tumour, surgery or radiation. It is chronic and incurable and requires lifelong management. Lymphoedema can affect people of all ages and can occur in any part of the body. It may not occur for sometime after the initial trauma or surgery and patients remain at risk of developing Lymphoedema for the remainder of their lives. Lymphoedema affects individuals physically, psychologically and socially. It has a significant impact on quality of life and the ability to undertake normal activities of daily living.

1.2 In December 2009, Welsh Government published the Strategy for Lymphoedema in Wales and the main aims of the Strategy were to:

- Raise the awareness of Lymphoedema and how simple treatment strategies could improve patient’s quality of life
- Improve health and well being by empowering patients to maximise their own independence and minimise the risks associated with Lymphoedema
- Integrate, develop, reconfigure and more effectively plan and manage Lymphoedema services throughout Wales in line with the seven Health Boards and Velindre NHS Trust
- Improve patient access to Lymphoedema services ensuring that patients receive the right treatment at the right time by the right professional in the right place
- Provide a comprehensive preventative approach to all patients at risk of developing Lymphoedema thereby reducing the demand on other NHS services
- Build on the strengths of the current tertiary and secondary care Lymphoedema services integrating services across organizational boundaries incorporating community, primary care and social services
- Develop and build on the current available Lymphoedema education enabling health care professionals to easily access local courses to implement in their own practice
- Clarify the actions needed to implement Lymphoedema services across Wales and improve service delivery

1.3 A National Clinical Lead for Lymphoedema was appointed to facilitate the implementation of the Strategy within NHS Wales and part of the development process has included the review of services that support the management and care of Lymphoedema patients to identify areas
for improvement.

1.4 In June 2012 following on from patient complaints that the correct compression garments were not being prescribed or dispensed in a timely manner an audit utilising data on the CASPA (Comparative Analysis System for Prescribing Audit) was undertaken. Data on 50 prescriptions dispensed in Abertawe Bro Morgannwg University Health Board and 50 in Betsi Cadwalader Health Board were analysed and the results showed that 50% of dispensed compression garments were incorrect, including wrong size, style, classage and quantity.

The main issues highlighted were:-

- Made to measure garments were being substituted with readymade garments which would have caused harm if worn.
- Upper limb arm sleeves were being prescribed without mitt coverage thus causing hand oedema
- The number of garments provided was being reduced to one instead of two meaning patients were not able to wash and dry them appropriately.
- The length of time taken to access the garments was unsatisfactory; with the average wait experienced by patients being 6 weeks as oppose to a few days.
- Additional costs were being incurred for postage, packaging and manufacturer and wholesaler charges. These charges were incurred by the pharmacy contractor and were not reimbursed by NHS Wales. This is resulting in many pharmacies supplying at a loss.
- Even though all relevant details on the garments, including PIP codes, were given to primary care, GP’s found the process extremely difficult and time consuming.

The outcome of the audit showed that there was waste harm and variation in compression garments being prescribed and dispensed.

1.5 Following the completion of the audit it was agreed that the findings would be discussed with relevant stakeholders (All Wales Medicines Management Board and CPC Wales representatives) to determine an appropriate mechanism for improving the service provided to Lymphoedema patients.

1.6 In addition, the Lymphoedema services are actively working with Procurement colleagues in NHS Wales Shared Services to develop an “All Wales Lymphoedema Contract” which will include a comprehensive list of compression garments and lymphoedema products. The contract will consist of a series of lots, of which there are several, that will be awarded to one supplier. All products will be independently tested by SMTL (Surgical Material Testing Laboratory) ensuring the best products at the best price. Once the contract process is complete An All Wales Lymphoedema Formulary will be devised for use in primary and secondary care certifying all patients has access to the best evaluated and priced lymphoedema products. The contract process has begun and we are aiming for the Lymphoedema Formulary to be available by
October 2014.

2 **Objectives**

An initial meeting of the Lymphoedema Pharmacy Working Group (LPWG) was held in June 2013 and the audit findings were discussed. As a result of this initial meeting it was agreed that Community Pharmacy Wales (CPW) would be happy to work collaboratively with, the group. The group would seek to work collaboratively with key stakeholders to critically examine the audit information obtained and identify areas for improvement.

2.1 Initial areas identified included :-

- Critical analysis of the current supply chain for the provision of Lymphoedema garments, identifying current waiting times, prescribing of correct garment and quantity, details regarding correct manufacturer contacts as well as compression garments descriptions and appropriate PIP codes.

- Development of an alternative model for the dispensing of Lymphoedema garments, with the emphasis on reducing harm, variation and waste.

Initial discussions between the Lymphoedema service and CPW colleagues have already identified a number of areas within the existing prescribing / dispensing process that could be improved with minimal effort. Improvements will be dependent on effective collaboration between key stakeholders and the Lymphoedema service.

- Implementation of a pilot study to test the proposed model. (Annex 1)

Following discussion it was suggested that the following Health Board areas be considered for the purpose of the pilot study: :-

a) Abertawe Bro Morgannwg University Health Board (ABMUHB)
b) Cwm Taf Health Board (CTHB)

- Evaluation of the pilot study and the development of recommendations for future working.

3 **Scope**

The scope of the initial work will focus on South Wales and will include the following stakeholders: -

- Abertawe Bro Morgannwg University Health Board and Cwm Taf Health Board Lymphoedema Service
- National Lymphoedema Posts
- Community Pharmacy Wales
The following areas are excluded from the scope of this work:

- Other HB lymphoedema services at present

### 4 Timescales and Deliverables

The Timescales for the completion of this work are:

<table>
<thead>
<tr>
<th>Deliverables</th>
<th>Date</th>
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<tbody>
<tr>
<td>Terms of Reference submitted to the CPW Board and a mandate sought on behalf of the All Wales Medicine Management Board</td>
<td>18th July 2013</td>
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<tr>
<td>Formally establish Community Pharmacy Wales and the All Wales Lymphoedema Service Collaboration Project</td>
<td>26th July 2013</td>
</tr>
<tr>
<td>First Meeting the Community Pharmacy Wales and the All Wales Lymphoedema Service Collaboration Board to:</td>
<td>26th September 2013</td>
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<tr>
<td>- Agree plan for pilot study</td>
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<tr>
<td>- Agree Evaluation criteria</td>
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<tr>
<td>- Agree Engagement Plan Second Meeting</td>
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<tr>
<td>- Agree Project Plan/ Project Structure and Arrangements</td>
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<tr>
<td>Melanie Thomas and Karen Morgan to submit pilot guidance to be circulated to Project Board for comments</td>
<td>4th October 2013</td>
</tr>
<tr>
<td>Comments on pilot guidance to be received from Project Board</td>
<td>11th October 2013</td>
</tr>
<tr>
<td>All Wales Lymphoedema Service and Community Pharmacy Wales leads to send formal communication to stakeholders</td>
<td>W/C 14th October 2013</td>
</tr>
<tr>
<td>Pilot Study begins</td>
<td>4th November 2013</td>
</tr>
<tr>
<td>Progress Report presented to All Wales Medicines Management Board and the Community Pharmacy Wales Board</td>
<td>15th November 2013</td>
</tr>
<tr>
<td>Second meeting of Community Pharmacy Wales and the All Wales Lymphoedema Service Collaboration Board to:</td>
<td>28 January 2014</td>
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<tr>
<td>- Review progress of pilot</td>
<td></td>
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<tr>
<td>- Agree earlier improvements that have been identified by the pilot study that can be implemented across NHS Wales</td>
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<tr>
<td>- Develop and update report for Medicines Management Board and the CPW Board</td>
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## 5 Resources & Membership

The proposed membership of the Lymphoedema Pharmacy Working Group will be:

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melanie Thomas</td>
<td>National Clinical Lead for Lymphoedema, NHS Wales</td>
<td>Abertawe Bro Morgannwg Health Board/Working with Welsh Government</td>
</tr>
<tr>
<td>Jane Fitzpatrick</td>
<td>Director, Lymphoedema Services Strategy Programme</td>
<td>Public Health Wales/Working with Welsh Government</td>
</tr>
<tr>
<td>Steve Simmonds</td>
<td>Head of Community Pharmacy Wales Policy Unit</td>
<td>Community Pharmacy Wales</td>
</tr>
<tr>
<td>Karen Morgan</td>
<td>National Lymphoedema Education and Research Specialist</td>
<td>Abertawe Bro Morgannwg Health Board/Working with Welsh Government</td>
</tr>
<tr>
<td>Jayne Howard</td>
<td>Regional Director</td>
<td>Community Pharmacy Wales</td>
</tr>
<tr>
<td>Hugh Thomas</td>
<td>Regional Director</td>
<td>Community Pharmacy Wales, Mid &amp; West Wales</td>
</tr>
<tr>
<td>Steve Davies</td>
<td>Pharmacy Superintendent</td>
<td>A.E Sheppard Ltd</td>
</tr>
<tr>
<td>Karen Wingfield</td>
<td>Lead Lymphoedema Specialist</td>
<td>Cwm Taf Health Board</td>
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Third meeting of the Community Pharmacy Wales and the All Wales Lymphoedema Service Collaboration Board to:
- Review Progress
- Develop final reporting format / content

Pilot Study ends 4th May 2014

Evaluation of Pilot Study and production of final report By 31st July 2014

Fourth meeting of the Community Pharmacy Wales and the All Wales Lymphoedema Service Collaboration Board to:
  a) Finalise Report and recommendations

Report presented to All Wales Medicines Management Board and the Community Pharmacy Wales Board August 2014
6 Dependencies & Constraints

The key constraints for this programme of work are:

- Challenging timescales for completion of the work
- Availability of key resources to undertake the pilot work due to existing work commitments etc
- Constraints to community pharmacies in receiving education

ANNEX 1: The Pilot Process

A new prescription advice form will be developed to be utilised in ABMUHB and CTHB. The process will be slightly different in each HB comparing the process utilising non medical nurse independent prescribers versus utilising the GP to formulate the Prescriptions identifying differences in waste, harm and variation.
The new Prescription advice sheet will be specifically formatted to include:
- Patients details
- GP details
- Pharmacy details
- Compression garments manufacturer contact details so pharmacies can contact direct reducing unnecessary add on charges and time delays if the pharmacy chooses to avail themselves of this arrangement
- Product description including size, colour, classage, style
- PIP CODE

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Patient</th>
<th>GP</th>
<th>Community Pharmacy</th>
<th>Community Pharmacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>CTHB</td>
<td>Attends lymphoedema clinic issued with new prescription advice sheet- triplicate copied  a) Sent to community pharmacy as advised by patient  b) Sent to GP  c) Patients own copy</td>
<td>Attends GP for prescription and awaits confirmation when prescription will be ready</td>
<td>Prescription given to pharmacy awaits date when garment will be available</td>
<td>Returns to pharmacy to pick up compression garment</td>
</tr>
<tr>
<td>ABMUHB</td>
<td>Attends lymphoedema clinic issued with prescription for compression garment  Advice sheet sent to community pharmacy as advised by patient</td>
<td>N/A</td>
<td>Prescription given to pharmacy awaits date when garment will be available</td>
<td>Returns to pharmacy to pick up compression garment</td>
</tr>
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- Lymphoedema contact details for queries
- Date issued

Additionally training will be provided by each of the lymphoedema teams for community pharmacists in Lymphoedema management and the new pilot process