This is an author produced version of a paper published in:

*British Journal of Nursing*

Cronfa URL for this paper:

http://cronfa.swan.ac.uk/Record/cronfa36200

---

**Paper:**


---

6 month embargo.

This item is brought to you by Swansea University. Any person downloading material is agreeing to abide by the terms of the repository licence. Copies of full text items may be used or reproduced in any format or medium, without prior permission for personal research or study, educational or non-commercial purposes only. The copyright for any work remains with the original author unless otherwise specified. The full-text must not be sold in any format or medium without the formal permission of the copyright holder.

Permission for multiple reproductions should be obtained from the original author.

Authors are personally responsible for adhering to copyright and publisher restrictions when uploading content to the repository.

http://www.swansea.ac.uk/library/researchsupport/ris-support/
Evaluation of the Economic Impact of a National Lymphoedema Service in Wales

Ioan Humphreys¹*
Melanie J Thomas²

¹College of Human and Health Sciences, Swansea University
*Corresponding author
²National Clinical Lead for Lymphoedema in Wales, NHS Wales

* Correspondence: i.humphreys@swansea.ac.uk

KEY WORDS

Lymphoedema, Cancer, Impact, Wales, Economic,

The Corresponding Author confirms that the authors named on the paper ‘Evaluation of the Economic Impact of a National Lymphoedema Service in Wales’ declare no competing interests.
Abstract

Lymphoedema Network Wales has focused on maximising the impact of its service through the effective use of available resources to ensure high quality and consistent care for people with lymphoedema across Wales. The aim of this evaluation was to estimate the economic impact of a National lymphoedema service on the NHS Wales budget. Work was undertaken to determine the care pathway within Lymphoedema Network Wales and develop a hypothetical ‘world without’ the service as a comparator. The four groups of patients that made up the pathways were ‘Group 0 At Risk’, ‘Group 1-2 uncomplicated lymphoedema’, ‘Group 3 Complicated/Complex’ and ‘Group 4 Palliative Care’. Overall resource utilisation between the six month ‘pre’ and six month ‘post entry’ indicated that there were significant resource reductions to be seen after lymphoedema service entry for all patients in each group. This evaluation provides estimates that suggest that the service is likely to be cost saving when people with lymphoedema are managed within Lymphoedema Network Wales rather than in a ‘world without’ the service.

Introduction

Lymphoedema is a long-term (chronic) condition that causes swelling in the body’s tissues due to lymphatic system failure. It can affect any part of the body, but usually develops in the arms or legs. (NHS UK 2017). It is an incurable condition and requires lifelong management (Moffatt, et al., 2003). Lymphoedema can affect people of all ages and can occur in limbs, the head and neck, trunk or genital area. It may not become apparent for some time after trauma or surgery, and patients remain at risk of developing lymphoedema for life (Morgan, Franks & Moffatt, 2005).

It has a profound effect on people’s quality of life (QoL) and their ability to engage in normal daily activities (Ridner, 2009). It has a significant impact on NHS resources as patients have a number of hospital admissions for cellulitis infections related to their lymphoedema (Moffat, et al., 2003). Evidence supplied by Lymphoedema Network Wales indicates that the prevalence rate for the condition in Wales is currently more than 5.49 per 1,000 populations, with a
prevalent population of over 17,000 people with the condition receiving treatment and signs that these numbers are increasing (Thomas & Morgan, 2017).

The 2009 Strategy for Lymphoedema in Wales set out key actions for local health boards in delivering services; with emphasis on a whole system approach to ensure care can be provided most appropriately and efficiently. Up until January 2012, there was wide variation in the organisation and delivery of lymphoedema services across Wales. Some trusts had commissioned full lymphoedema services; others offered services that can only be accessed by cancer patients. Some individual health boards did not provide any services. Since January 2012, six new services were developed in health boards and localities (Bridgend, Ceredigion, Cwm Taf, Aneurin Bevan, Cardiff & Vale and Powys), based on the 2009 strategy. The current caseload is increasing per quarter with many patients giving detailed histories of their long wait for adequate lymphoedema services which has affected their QoL.

**Evaluation aim and objectives**

The aim of this evaluation was to estimate the economic (cost) impact of Lymphoedema Network Wales on the NHS Wales budget. The objectives were to:

- Quantify the likely cost burden associated with lymphoedema in Wales.
- Assess the wider costs to patients and families resulting from lymphoedema.
- Estimate the financial benefits associated with the services provided in Wales.

**Methods**

The Lymphoedema Network Wales team administered a resource utilisation questionnaire (RUQ) that was created by the research team. The RUQ was developed reflecting service usage across primary care (e.g. GP visits, community care), secondary care, personal social services, and wider usage such as community pharmacist services. Two questions were added to give a summary of patient satisfaction to provide an indication of a patient-reported outcome associated with the service. We also consulted relevant guidelines on the management of lymphoedema from the British Lymphoedema Society (British Lymphology Society, 2001), the

Due to the absence of a ‘world without’ the service comparator for the evaluation (as the service is fully established in Wales with no historical control available); the questionnaire was administered in two parts. The first part asked the selected patients for their resource utilisation six months prior to entering the Lymphoedema Service. The second part asked for their resource utilisation six months post entering the Lymphoedema Service. This enabled a pre/post estimation to be made for these patients in order to generate a hypothetical ‘world without’ comparator. Participants completed the questionnaires using recall, but were then verified via their case notes and electronic medical data systems. Participants were purposively recruited from each of the seven lymphoedema services across Wales by the clinical lead specialists. The patients were asked to contribute in a route clinical lymphoedema assessment cross sectionally across Wales in the second week in January 2015. Each patient that was seen was asked if they wanted to contribute with a maximum of seven participants from each. All data were fully anonymised prior to analysis and ethical approval was granted from both Abertawe Bro Morgannwg University Health Board (ABMUHB) and Swansea University for analysis of the data.

Development of Model Structure

The design and structure of the lymphoedema service costing model was based on several inputs, each informed by the patient related information obtained from the lymphoedema service clinical lead interviews from the UHBs and the RUQs administered to patients. Also, based on information from the clinical leads’, estimated resource utilisation for these groups, as well as referral and caseload rates, were developed into four comparator group ‘types’ to compare with the baseline cost. These were:

- ‘Group 0 At Risk’ – 11% of annual caseload,
- ‘Group 1-2 Uncomplicated’ – 44% of annual caseload,
- ‘Group 3 Complicates/Complex’ – 40% of annual caseload and
- ‘Group 4 Palliative Care’ – 5% of annual caseload

Finally, the four cost inputs were combined with the total ‘per UHB Lymphoedema Service’ staff costs to illustrate a ‘per UHB’ ‘cost’, as well as a ‘National Wales Lymphodema Service’ cost.
Data inputs

The costing model was constructed based on information provided by Lymphoedema Network Wales information garnered from the fifty patient RUQs. The model uses ‘current’ resource utilisation costs (PSSRU 2013) combined with the caseload numbers for each Health Board and the % of those patients attributed to each of the four groups. This information was again provided by Lymphoedema Network Wales. The overall yearly running costs of each individual health board service were input into the model to create an overall ‘All-Wales’ running cost. These data was compiled by adding up the number of staff in each centre by their grade band and FTE equivalent.

To establish a ‘base case’ scenario that represented a ‘world without’ service comparison the RUQ was used to collect service user data from the fifty patients in lymphoedema services across Wales. The total cost of the 50 patient’s utilisation in primary and secondary care was £242,944. This equates to £4,859 per person in the baseline target group. Due to time and resource constraints, this does not include medication and/or appliance costs (such as garments or dressings). However further studies by the authors have illustrated significant cost savings in dressings with lymphoedema collaboration (Thomas & Morgan, 2017).

Results

Resource utilisation

The mean resource utilisation for each category is shown in Table 1. The overall cost savings and resource utilisation between the six month ‘pre lymphoedema service entry’ and the six month ‘post’ utilisation for the 50 patients is highlighted. There were significant savings to be seen, in particular GP Surgery Visits (£8,944), GP Home visits (£6,490), Practice Nurse appointments (£27,136), District Nurse calls (£51,380), Care Assistants (£15,270) and episodes of Cellulitis (£6,148). There was an overall saving of £132,104 across the 33 resource items analysed giving a mean overall per patient saving of £2,642.

Table 1. Selected differences in resource utilisation
<table>
<thead>
<tr>
<th>Resource Pre Lymphoedema Service Involvement</th>
<th>Cost</th>
<th>Resource- Post Lymphoedema Service Involvement</th>
<th>Cost</th>
<th>Cost Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline GP Surgery</td>
<td>£15,136</td>
<td>Six Months GP Surgery</td>
<td>£6,192</td>
<td>-£8,944</td>
</tr>
<tr>
<td>Baseline GP Home</td>
<td>£8,470</td>
<td>Six Months GP Home</td>
<td>£1,980</td>
<td>-£6,490</td>
</tr>
<tr>
<td>Baseline District Nurse Home Home</td>
<td>£71,540</td>
<td>Six Months District Nurse Home Home</td>
<td>£20,160</td>
<td>-£51,380</td>
</tr>
<tr>
<td>Baseline Care Assistant</td>
<td>£39,150</td>
<td>Six Months Care Assistant</td>
<td>£23,880</td>
<td>£15,270</td>
</tr>
<tr>
<td>Baseline Cellulitis</td>
<td>£8,120</td>
<td>Six Months Cellulitis</td>
<td>£1,972</td>
<td>-£6,148</td>
</tr>
</tbody>
</table>

**Costing model**

The base case results of the six month resource utilisation for the fifty patients before entering a lymphoedema service was £4,859 However, this is for six months so to extrapolate to an annual cost, this has been multiplied by two to get £9,718.

When the pathway costs are combined and compared with the individual running costs of each of the lymphoedema groups it showed cost savings (see Table 2). The population of the active lymphoedema case load in 2015 was 9225 patients in Wales. Thus the lymphoedema groups were populated with percentages provided by Lymphoedema Network Wales as was discussed previously. Estimated annual savings of £8,590,100 are seen for the Group 0 patients. Savings of £34,147,036 are seen for the Group 1 – 2 patients. An estimated £21,673,683 savings compared with the ‘world without’ the service estimates are seen for Group 3 and an estimated £270,553 savings for Group 4 patients.

**Table 2 Lymphoedema Service Pathway results (All-Wales)**

<table>
<thead>
<tr>
<th>Group 0 at risk total per person cost</th>
<th>£903</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>1015 (11%)</td>
</tr>
<tr>
<td>Total estimated resource utilisation Cost</td>
<td>£916,053</td>
</tr>
<tr>
<td>Intervention Cost</td>
<td>£356,012</td>
</tr>
<tr>
<td>Overall Cost</td>
<td>£1,272,065</td>
</tr>
<tr>
<td>Estimated No pathway cost</td>
<td>£9,862,166</td>
</tr>
<tr>
<td>Cost Savings</td>
<td>£8,590,100</td>
</tr>
</tbody>
</table>

| Group 1-2 uncomplicated oedema total per person cost | £1,218 |
### Population 4059 (44%)

| Total estimated resource utilisation Cost | £4,945,616 |
| Intervention Cost                         | £356,012   |
| Overall Cost                              | £5,301,628 |
| Estimated No pathway cost                 | £39,448,664 |
| Cost Savings                              | £34,147,036 |

### Group 3 complicated complex total per person cost £3,748

| Total estimated resource utilisation Cost | £13,832,726  |
| Intervention Cost                         | £356,012     |
| Overall Cost                               | £14,188,739  |
| Estimated No pathway cost                  | £35,862,422  |
| Cost Savings                               | £21,673,683  |

### Group 4 Palliative care total per person cost £8,360

| Total estimated resource utilisation Cost | £3,856,237  |
| Intervention Cost                         | £356,012    |
| Overall Cost                               | £4,212,250  |
| Estimated No pathway cost                  | £4,482,803  |
| Cost Savings                               | £270,553    |

### Summary of findings

The potential costs associated with lymphoedema and its management in Wales are considerable. Our study of fifty Lymphoedema Network Wales patients’ six months prior to their entry to the lymphoedema service resource utilisation shows a mean cost per patient cost of £4,859 for the six months or £9,718 as an annual estimate.

When the mean cost per patient is multiplied by the lymphoedema service’ annual active caseload (based in 2015) of 9,226, the potential costs equate to an estimated £89,656,054 for lymphoedema management in a ‘world without’ the service – i.e. if they were not supported by the Lymphoedema Network Wales service. However, caution needs to be exercised in this estimation as multiplying these results to the current cases are a simple extrapolation.
The cost estimates indicated above are estimates based on an NHS perspective as the data was not sufficient to allow any reliable assessment of the wider societal costs of lymphoedema. The debilitating and life limiting nature of lymphoedema suggest the wider societal costs are considerable if family and friends care burden is taken into account. This combined with losses to productivity; intangible costs linked to health-related QoL issues make the overall societal cost burden of lymphoedema extensive and an important issue for future consideration.

The six month estimates of ‘post-entry’ Lymphoedema service utilisation mean per patient cost of £2,217 indicates an overall estimated potential saving of £2,642 per patient compared with the pre service entry estimates. If these estimates are extrapolated to the caseload of 9226, in a lymphoedema service indicates an annual resource utilisation of £40,904,394, which when compared with the ‘world without’ the service suggests an annual saving to NHS Wales of £48,751,660 (‘pre’ service £89,656,054 – ‘post’ service £40,904,394).

**Discussion**

This evaluation of Lymphoedema Network Wales indicates that - compared to a ‘world without’ lymphoedema care, the service is delivering efficiencies to the NHS, particularly in terms of primary health care resources utilised. Primary care savings are seen for visits to Practice Nurses, District Nurses and Physiotherapists and when these are formally analysed in a costing model, these appear to be the main drivers of cost savings. However, caution must be given to the moderate-high uncertainty in these savings being realised given the threshold analysis undertaken, especially for Group 4 (palliative) patients. This small study suggests an immediate need to prospectively evaluate lymphoedema services over a longer period of time; and consider in-depth different models of care delivery across Wales to develop understanding of what elements drive efficiencies. This evaluation has focused on the health care resources used and related cost rather than undertaking a full economic analysis to fully compare the costs of delivering Lymphoedema Network Wales against the change in health benefits, particularly in the translation of these benefits to patient outcomes such as QoL.

**Limitations**

There are several key limitations of the study that need to be acknowledged. This study is an examination of the incremental costs rather than a full economic evaluation i.e. where incremental costs are compared against incremental outcomes. Thus, this only informs part of
the picture about the potential benefits and value of the lymphoedema service. There has been a small qualitative study (Watts & Davies, 2016) but no formal assessment of the service with regard to health benefits and the value placed on these benefits for patients.

The sensitivity analysis suggests that there is considerable uncertainty around our estimates. The threshold analysis also indicates uncertainty in our findings and suggests some of the findings are not plausible when caseload numbers and costs of services are varied. The lack of any formal outcome analysis and full economic analysis (e.g. to derive a cost per quality adjusted life year) in this evaluation means that ‘value for money’ estimates for the service, in line with NICE recommendations (£20,000 - £30,000 cost per QALY threshold) were not possible and need to be considered for future evaluations.

The main cost drivers compared with the ‘world without’ the service are the GP Surgery Visits, Practice Nurse and District Nurse visits. This will no doubt vary from centre to centre based on local practice. Lymphoedema Network Wales uses a system of a one-stop clinic compared with usual care in the other health boards. This is different to other local services and we suggest the differences between the services needs to be explored further.

**Conclusion**

The evaluation of cancer-related Lymphoedema treatment programmes (Shih, et al., 2009; Stout, et al., 2013; Stout, et al 2012) and the possible consequential post treatment economic burden provides an excellent scenario for illustrating the complexities involved in attempting to integrate the evidence relating to rehabilitation effectiveness and resource utilisation. Therefore, further cost analysis research is needed to estimate the economic burden of these patients on the NHS and social services within the UK and thus evidence is welcomed and needed to prove whether this can have an impact on current public health policies. This evaluation indicates a considerable cost burden of lymphoedema to NHS Wales and provides estimation of the potential for cost saving when people with lymphoedema are managed within lymphoedema services rather than undiagnosed/misdiagnosed frequent users of both primary and secondary care.

Further work by the Lymphoedema Network Wales will be able to capitalise on this evaluation to provide on-going evidence of the ‘real-world’ economic impact of the service alongside all
other aspects of delivery which exemplify this service as a model of prudent health care (Aylward, et al., 2013, Drakeford 2014; Bradley, Wilson, et al., 2014).

References

NHS UK http://www.nhs.uk/conditions/Lymphoedema/Pages/Introduction.aspx (Last accessed 5th September 2017)


Personal Social Service Research Unit (PSSRU 2013) http://www.pssru.ac.uk/project-pages/unit-costs/2013/ (last accessed 1st December 2014)


