

**Policy/Service Title: Community Based Lymphoedema Service
Equality Impact Assessment Report
Date: 11.2 09**

**Co-ordinator of Policy or Service: Sue Townley
Persons carrying out Equality Impact Assessment: Sue Townley**

1. Introduction

The aim of this service is to provide a community based lymphoedema service for adults 18yrs and over with non cancer related lymphoedema/chronic oedema (often referred to as primary lymphoedema) in order to optimise their physical, psychological and social wellbeing, reduce and prevent complications and enable them to remain active both at home and in the community.

The service will make a significant contribution to the overarching aim of providing a comprehensive and responsive lymphoedema service in BANES within primary, secondary and hospice care settings for individuals with primary and secondary lymphoedema/chronic oedema, with and without a cancer diagnosis, thus ensuring equity of access for all individuals affected by lymphoedema of whatever aetiology.

2. What data was analysed as part of this Equality Impact Assessment and what did it tell us?

The need for such a service identified nationally and locally. In recent years there has been an increased awareness of lymphoedema, its prevalence and inadequate care. National standards for care and best practice for the management of lymphoedema (2006) and templates for the development of lymphoedema services (2007) have been developed.

Importantly there has been growing recognition that lymphoedema has causes other than cancer. However, problems remain in terms of inequitable service provision for people with lymphoedema. The belief held by many professionals historically that lymphoedema is only related to cancer has influenced the development of many lymphoedema services, in that they only treat cancer related lymphoedema. Consequently, many patients continue to receive inadequate treatment, are unaware that treatment is available or do not know where to seek help.

A mapping exercise was undertaken in March 2008 to establish what currently exists in terms of lymphoedema services in NHS BANES, who provides them i.e. specialist and generalist care providers, and how this fits with the national picture in terms of lymphoedema service provision. Key issues arising from the mapping exercise were:

- The development of services in BANES is similar to other areas, in that the focus has been cancer treatment related lymphoedema (secondary lymphoedema), provided in secondary care settings i.e. RUH Lymphoedema service, and hospice based lymphoedema services for palliative care patients with lymphoedema i.e. Dorothy House Hospice care Lymphoedema service.
- Services exist for palliative/specialist palliative care patients with mild, moderate severe/complex lymphoedema in primary care and hospice settings and to a lesser extent in secondary care settings.
- Services exist for patients with cancer related lymphoedema – mild, moderate, severe/complex in primary and secondary care settings although in primary care settings it could be stronger.
- There is a gap in service provision for people with primary lymphoedema i.e. a non cancer diagnosis in NHS BANES.
- There is a gap in service provision for people with complex/severe lymphoedema/oedema with a non cancer diagnosis in NHS BANES.
- A skills gap exists in the assessment, management and monitoring of patients with mild to moderate lymphoedema/chronic oedema in primary care.
- There is a gap in BANES PCT regarding a lymphoedema nurse specialist (LNS) to work in partnership with the tissue viability nurse and community practitioners e.g. community matrons, community nurses, practice nurses.

There is insufficient local data to inform service development, in particular numbers of individuals with primary lymphoedema in BANES PCT. The Advanced Lymphoedema Nurse Practitioner (ALNP) at the RUH has kept data 2000 - 2008 regarding individuals referred inappropriately to the cancer related lymphoedema service at the RUH with non cancer related lymphoedema/chronic oedema. Whilst useful, the ALNP acknowledges this is an under representation of people with primary lymphoedema. Cross and Raffle (2002) estimate the approximate number of newly arising cases of lymphoedema each year in each PCT is likely to be of the order of 70, of which about 6 will have a diagnosis of primary lymphoedema. This figure was

derived from the available literature and the authors are quick to point out that that this figure is only as accurate as the study data on which it is based. The mapping exercise referred to above confirmed the existence of some good, robust and effective services for many individuals with lymphoedema/chronic oedema, but it also highlighted some gaps, in particular a gap in service provision in BANES for individuals with non cancer related lymphoedema/chronic oedema. In order to move forward quickly and use the monies invested in this service development, the ALNP and LNS from the RUH and Dorothy House agreed to work jointly 30hrs per week for a seven month interim period (Sept 08 – March 09) implementing 'phase one' of this service development. The focus of phase one has been setting up the service and beginning to deliver a teaching programme to key health practitioners in the basic management and monitoring of patients with mild to moderate lymphoedema/chronic oedema. It has also focused on the development and implementation of systems/processes to identify individuals with non cancer related lymphoedema/chronic oedema in BANES, given the data gap highlighted above.

The commissioning specification for this service builds on phase one and reflects phase two of this service development, namely a community based lymphoedema service which will comprise of a full time lymphoedema nurse specialist (LNS). The commissioning specification has been produced in the context of national and local background information outlined above and has been informed by relevant health and social care policy initiatives. It also reflects the feedback from practitioners working in primary, secondary and hospice care settings and individuals with lymphoedema.

3. Assessment of impact on equality groups

Gender - Neutral Impact
Disability - Positive impact, in those individuals with impaired mobility due to lymphoedema will now have access to a service that will provide the treatment and management required to reduce the lymphoedema and the associated problems e.g. impaired mobility.
Age - Neutral Impact. The commissioning specification states the service is for adults 18yrs and over. The rationale for this has been informed by information obtained from various consultation processes outlined in 1.4 and 2.1. namely it is anticipated the majority of people accessing this service will be 18years and over. Children and young people under 18yrs will have their needs met by children's services. This issue will need to be monitored and discussed by service providers and commissioners on an ongoing basis.
Race - Neutral Impact

Sexual orientation - Neutral Impact
Religion/belief - Neutral Impact

4. Monitoring arrangements

The contract will be monitored by NHS B&NES and the PBC exec. Every month the service provider will supply key statistical information (KPI) on activity levels and outcomes for the service to the commissioner.

There will be quarterly review meetings between provider and commissioner. The service provider will provide an annual report. These monitoring activities will contribute to decisions made re. a service change.

5. Conclusions and action plan

See attached action plan

Signed off Janet Rowse
Deputy CEO
NHS Bath & North East Somerset

Date 27 July 2009

Bath and North East Somerset Council Equality Impact Assessment Improvement Plan

Please list actions that you plan to take as a result of this assessment (continue on separate sheets as necessary). These actions need to be built into the service planning framework and targets should be measurable, achievable, realistic and time bound.

Title of service/function or policy being assessed: community based lymphoedema service

Name and role of officers completing assessment: Sue Townley project manager commissioning

Date assessment completed: 11.2.09

Issues identified	Actions required	Progress milestones	Officer responsible	By when
The KPI's for the service need to reflect the six equality strands	Amend the KPI's	N/A	ST	28.2.09
The potential to exercise discretion regarding working with patients with a cancer related lymphoedema and/or palliative patients with moderate, severe/complex lymphoedema. This will be known as 'phase three' of the service development,	Permission for the provider to exercise discretion in phase three. This will normally be triggered by an individual patient's wish to receive their ongoing lymphoedema management closer to home as opposed to an acute trust or hospice. The decision to transfer care in this way will be a joint one i.e. the patient, and the relevant lymphoedema service providers.	Exercising discretion i.e. 'phase three' of this service development will only be implemented once phase two has been implemented and established. Phase three will need to be monitored and discussed by service providers and commissioners at quarterly review meetings and additional criteria developed/changes to the service made if it becomes necessary to do so.	ST	Ongoing

<p>A shortage of Lymphoedema Nurse specialists could result in the provider being unable to deliver the service</p>					<p>Commissioner to work with the provider to ensure the service is achieved</p>	<p>Work together throughout the advertising and recruitment process.</p> <p>Continuing monitoring and discussion at quarterly review meetings</p>	<p>ST</p>	<p>April 09</p> <p>Ongoing</p>
<p>The need to obtain feedback from service users given this is a new service</p>	<p>Commissioner to ensure the provider has mechanisms in place to carry out patient satisfaction surveys</p>	<p>Monitor and discuss at quarterly review meetings</p>	<p>ST</p>	<p>Ongoing</p>				

Once you have completed this form, use it as a basis for writing a report of the Equality Impact Assessment. Keep a copy of the form and report as a record of the processes you have been through in carrying out the EIA. Email one copy to the Equalities Team (equality@bathnes.gov.uk), and post a copy on the shared drive J:\Keynsham_S_Drive\Corporate Equality Group