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In 2014 Scotland Welcomes the World



Dear Colleague

**SMASAC, SHORT LIFE WORKING GROUP REPORT ON LYMPHOEDEMA - LYMPHOEDEMA CARE IN SCOTLAND, ACHIEVING EQUITY AND QUALITY**

It has been recognised that in Scotland there is currently a wide variation in the organisation and delivery of lymphoedema services, linked to a lack of appropriate data recording. Therefore, in June 2012, the Scottish Medical and Scientific Advisory Committee (SMASAC) convened a short life working group with a view to producing national recommendations on the treatment of people with or at risk of lymphoedema.

We are pleased to bring to your attention their report: "Lymphoedema Care in Scotland, Achieving Equity and Quality", which has been produced in partnership with the Macmillan Lymphoedema Project for Scotland. It may be found at - <http://www.scotland.gov.uk/Publications/2013/11/5016>

The report highlights the lack of awareness of the recent developments in the prevention and management of lymphoedema. The report also helps to identify how better care can be provided to patients and makes a number of practical recommendations, some of which have the potential, to make more effective use of resources for example revising the prescribing formularies to take account of evidence for the use of antibiotics, supportive garments, bandages, etc. In particular, prevention and timely and appropriate management could improve the quality of life of patients, reduce the stress to carers, and better utilise scarce healthcare resources.

The suggested approach is that of co-ordinated, equitable and accessible services across Scotland, supported by developing education and training of appropriate skills and knowledge for health professionals.

**From the Acting Chief Medical Officer**

**Dr Aileen Keel CBE,**

**Chief Pharmaceutical Officer  
Professor Bill Scott BSc MSc  
FRPharmS, and**

**Chief Nursing Officer  
Ros Moore RGN RNT BSc  
(Hons) Nursing, MA**

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18 July 2014

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**Addresses**

For action

Chief Executives, NHS Boards and Special Health Boards  
Directors of Nursing, to cascade to nurses, midwives, health visitors and AHPs  
Primary Care Leads  
Medical Directors to cascade to all doctors  
Directors of Pharmacy  
Scottish Cancer Taskforce

For information

Chairs, NHS Boards and Special Health Boards  
SMASAC  
NHS Board Directors of Public Health  
Cancer Regional Networks

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**Enquiries to:**

Policy Issues

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Medical Issues

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## Action

The report should be used as a working reference tool in the management and treatment of patients with lymphoedema and should be brought to the attention of other colleagues. The helpful references in the report can provide the evidence base for developing local pathways and reviewing formularies.

The report's recommendations are attached at Annex A and are targeted at those who have responsibility for taking them forward, with associated timescales for delivery.

There is a real prospect of improving services that will contribute to better quality outcomes for individuals, more effective person-centred care and better informed and motivated healthcare staff. We look to Boards to respond promptly and effectively to realise the potential benefits, and in line with recommendation 2 of the report, we would be grateful if Boards could each identify a key individual who will be responsible for leading on the report's recommendations within their areas. We propose to convene a national meeting for these leads, in order to assist their delivery and co-ordination of the report's recommendations. We would be grateful if you could provide contact details of these leads to [Michele.Aitken@scotland.gsi.gov.uk](mailto:Michele.Aitken@scotland.gsi.gov.uk) (Strategic Planning and Clinical Priorities Team ) Scottish Government by 1 October 2014.

We are very grateful to Dr John Gillies, the members of his working group, and the Macmillan Lymphoedema Project for Scotland for their work. We welcome your co-operation and look forward to working with you to implement the report's recommendations to improve the quality, equity and cost effectiveness of lymphoedema service provision in Scotland.

Yours sincerely,

*Aileen Keel*  
**DR AILEEN KEEL CBE**  
**Acting Chief Medical Officer**

*Ros Moore*  
**ROS MOORE**  
**Chief Nursing Officer**

*Bill Scott*  
**BILL SCOTT**  
**Chief Pharmaceutical Officer**

## Annex A

	<b>Recommendations</b>	<b>Action by:</b>	<b>Timing</b>
1.	<p>Health Boards should accurately identify incidence and prevalence of lymphoedema through improved coding at hospital discharge and in primary care.</p> <p>On confirmation of diagnosis the following READ codes are recommended:</p> <ul style="list-style-type: none"> <li>• G860. lymphoedema post mastectomy</li> <li>• G861. - other lymphoedema.</li> </ul> <p>ICD10 codes for lymphoedema: I89.0, I97.2, Q82.0 in any diagnosis position.</p>	Health Boards	<p>Appointed Leads to support implementation within 12 months or earlier:</p> <p>GP practices to record the diagnosis and the appropriate READ code provided</p> <p>Healthcare professionals in hospitals to record the diagnosis in the clinical records and the discharge summary to enable local medical coding staff to code it according to the recommended ICD10 codes</p>
2.	Health Boards should designate Leads for lymphoedema services who should be tasked with developing local pathways for the referral and management of lymphoedema based on existing evidence and guidance, to include management and prevention of cellulitis in people with established lymphoedema, and provision of advice on self-management.	Health Boards	To identify leads by 1 October 2014 to: Michele.aitken@scotland.gsi.gov.uk
3.	A SIGN guideline should be developed for the diagnosis, assessment and management of primary and secondary lymphoedema, to include prevention, early recognition and management of cellulitis in primary care. SIGN should consider including lymphoedema in the scope when updating relevant cancer guidelines.	Scottish Government will approach SIGN	Approach by 2015
4.	Healthcare Improvement Scotland should consider developing QPIs Quality Performance Indicators (QPIs) for the management of lymphoedema. Potential indicators	Healthcare Improvement Scotland (HIS)	Scottish Government to approach HIS to discuss the development of QPIs, linking it to existing relevant QPIs such as cancer QPIs, by end of 2014.

	<p>could include:</p> <ul style="list-style-type: none"> <li>• referral to lymphoedema specialist services/clinics by board area, including type of lymphoedema, referral source, and age ranges to determine equity across the lifespan</li> <li>• proportions of medical, nursing and AHP staff by board area who have had additional lymphoedema training</li> <li>• numbers of diagnoses in primary and secondary care</li> </ul>		
5.	Scottish Cancer Taskforce should also consider lymphoedema outcomes when proposing updates for relevant sets of cancer QPIs.	Scottish Cancer Taskforce	To be considered at the next meeting of the National Cancer Quality Steering Group.
6.	Health Boards should support and develop a community-based integrated model of tiered care for people with lymphoedema, including complications such as cellulitis applying the principles of integration.	Health Boards	Appointed Leads asked to report back to Scottish Government on developments by May 2015
7.	Health Board Leads together with regional planning groups should develop a national referral pathway for people with lymphoedema who require assessment for surgery for lymphoedema.	For appropriate pathways to be developed, we ask Health Boards and Regional Planning Directors to develop local/regional referral pathways	Appointed Leads asked to report back to Scottish Government on developments by May 2015
8.	NES should commission the development of basic educational modules in various formats for different professional groups - nurses, doctors, physiotherapists, podiatrists and social carers. Separate learning should be considered for non-registered staff as they have less background knowledge of the condition.	NHS Education for Scotland are asked to work with Health Board Leads to assess current educational tools and make recommendations to the Scottish Government on possible new educational models	Appointed leads are asked to report back by end of 2014
9.	Health Boards should raise awareness of lymphoedema and cellulitis and pathways for their management amongst health and social care professionals through education and training.	Health Boards	Appointed Leads asked to report back to Scottish Government on developments by May 2015

10.	All lymphoedema practitioners and specialists should have training in assisting individuals with lifestyle change.	Health Boards	Appointed Leads asked to report back to Scottish Government on developments by May 2015
11.	<p>Research should be undertaken for lymphoedema treatment to:</p> <ul style="list-style-type: none"> <li>• analyse the cost and benefits of treatment versus no treatment,</li> <li>• estimate the burden of disease and</li> <li>• identify wasteful treatments and strategies or avenues for savings in relation to lymphoedema treatment particularly in relation to:</li> <li>• provision of appropriate compression garments for each patient</li> <li>• prescription of ineffective treatments or unnecessary investigations and delays in treatment.</li> </ul> <p>The CSO should consider proposals for research in these areas.</p>	Chief Scientist Office (CSO) to consider proposals	<p>The CSO will consider proposals upon submission. Proposals, with a named lead researcher, who fits the criteria, should be submitted directly to the CSO.</p> <p><a href="http://www.cso.scot.nhs.uk/grants">http://www.cso.scot.nhs.uk/grants</a></p>