



Australian Non-Admitted Care Classification Development
Independent Hospital Pricing Authority
submissions.ihpa@ihpa.gov.au

Dear Sir/Madam,

The Lymphoedema Action Alliance is pleased to have the opportunity to respond in relation to the classification of the condition of **LYMPHOEDEMA** in the IHPA Australian Non-Admitted Care Classification Development Consultation.

The Lymphoedema Action Alliance (LAA) is focused on reducing the unnecessary suffering and burden of people living with lymphoedema. The LAA is made up of twenty organisations that have joined forces to be a more effective voice for improvements in treatment for lymphoedema. The LAA is working to ensure timely and equitable access to affordable lymphoedema services and compression garments regardless of where people live, their financial status and their health situation.

Lymphoedema is a chronic and debilitating condition of persistent swelling and thickening of skin caused by stagnation of lymph fluid in the affected body part. It mostly affects arms or legs, but the trunk, head, and genital area can be affected. It is caused by poor development or damage to the lymphatic system in the body. Lymphoedema is progressive and incurable. The early diagnosis and provision of best practice therapy are critical to improving physical, functional and emotional outcomes and reducing complications such as cellulitis episodes.

The LAA believes that lymphoedema is primarily a disease of the circulation. This is because the lymphatic system is a component of the circulatory system which returns interstitial fluid back into the vascular system.

The limited ability of patients with lymphoedema to access the public Tier 2 system has resulted in poor patient-level data-service accuracy. This data does not reflect the care needs of lymphoedema patients, and due to lack of timely intervention there is a likelihood of increased costly inpatient care to manage complications.

Please see the LAA's responses to the consultation questions below:

Do you agree with proposed approach to continue use of service event as the ANACC unit of count until non-admitted patient-level data become available?

The current service event approach has been detrimental to lymphoedema service provision and access. More effective non-admitted patient-level data needs to become available. This

can be achieved by the development and adoption of the proposed ANACC diagnostic groupings.

Do you agree with the proposed revised definition of a service event? How could it be improved?

The LAA agree that a service event should incorporate all types of treatment including assessment, examination and consultation, treatment and/or education. It should be expanded to incorporate documented services performed on behalf of the patient without the patient's presence, such as the ordering of compression garments. The importance of including assessment and education is consistent with the lymphoedema management principles and highlights the opportunity for early intervention and to prevent the more costly complications of chronic conditions.

Should the use of an episode count be introduced for selected relevant classes once sufficient patient level data is obtained under the new ANACC?

Concern is raised that the activity-based funding model is not appropriate for care of chronic conditions such as lymphoedema. The best outcome for patients with chronic conditions is stabilisation and long term self-management and this is not captured well in the episode count which is more applicable for acute self-limiting diseases.

Do you agree with using "presenting problem" as the main diagnosis-type variable for the future ANACC system? If yes, do you agree with the proposed definition of presenting problem"?

Yes, the LAA agrees that the inclusion of the presenting problem may provide improved data collection. However, in the context of lymphoedema, the diagnostic coding and intervention type grouping needs to be clearly established first.

Do you agree with the initial list of initial presenting problem/diagnosis-type and intervention-type groups presented at Appendix A? What refinements should be considered?

Lymphoedema is currently listed under 'MDC 05 Diseases and Disorders of the Circulatory System: Other disorder of the circulatory system' in Appendix A of the initial listing.

The LAA supports the listing of Lymphoedema as a circulatory disorder and that the correct location for its classification being MDC 05.

Lymphoedema has previously been inappropriately listed in a number of MDC classifications including disorders of the skin and of the breast. This has meant that the full spectrum of lymphoedema presentations has not been able to be recorded or that services are not able to be accessed.

In addition, the LAA requests that there be an adjustment to the grouping within the MDC 05 category. Lymphoedema requires its own category (similarly to peripheral vascular disorders).

People with lymphoedema represent significant groupings of people with different causation profiles, however the manifestation i.e. swelling of subcutaneous tissues of affected areas of the body is still a disorder of the circulatory system.

Previously, without its own clear diagnostic listing, lymphoedema has been invisible. There has been poor diagnostic coding accuracy for lymphoedema presentations and this has led to a lack of acknowledgement of care needs and access to services.

The LAA also recommends that “Lymphoedema Management” is included in the list of proposed intervention-type groupings. Lymphoedema Management is a complex multidisciplinary process undertaken by appropriately trained lymphoedema practitioners. This can include education, skin care, exercise, decongestive drainage and compression. Currently, without the listing of Lymphoedema Management, there has been minimal or poor quality non-admitted patient level data, compounding the difficulties of limited coding accuracy.

MDC 05 DISEASES AND DISORDERS OF THE CIRULATORY SYSTEM	
Proposed presenting problem/diagnostic type groupings	Proposes intervention-type groupings
LYMPHOEDEMA	LYMPHOEDEMA MANAGEMENT

What are the data elements that need to be created/collected in the Australian Non-Admitted Care Classification to support the interoperability of data sets for primary, secondary, and tertiary services?

The LAA acknowledges the importance of interoperability of data sets given that lymphoedema management is undertaken in primary, secondary and tertiary levels of service. We do note that currently, none of the levels of service have accurate diagnostic data sets for lymphoedema.

The Lymphoedema Action Alliance is keen to be informed of the outcome of this initial consultation and to contribute again in the future.

Yours sincerely,

The Lymphoedema Action Alliance Steering Committee