Towards an estimate of the prevalence of lymphoedema in Australia

A data source scoping report

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Contents

Summary

Lymphoedema is a condition where the accumulation of excessive amounts of protein-rich fluid in the tissue results in swelling of one or more regions of the body (ALA 2021). Lymphoedema occurs when the demand for lymphatic drainage exceeds the capacity of the lymphatic system and may develop due to a congenital malformation in the lymphatic system (primary lymphoedema), or due to damage to the lymphatic vessels or nodes (secondary lymphoedema).

Lymphoedema is a chronic condition requiring lifelong care. Treatment and management of lymphoedema requires care from a multidisciplinary team and the use of compression garments, which can be expensive. To help with this expense, Australian states and territories each have individual subsidy schemes for compression garments to assist those living with the condition.

There is currently no population-level prevalence estimate for the number of people in Australia living with lymphoedema. The purpose of this scoping study is to assess the utility of available data sources in determining an estimate of the number of Australian's living with lymphoedema.

What can the available data sources tell us about lymphoedema?

- In 2020–21, the age-standardised rate of hospitalisations for lymphoedema as the principal or additional diagnosis was 30 per 100,000 population (9,400 hospitalisations), with the rate higher for females (6,500; 40 per 100,000 population) than for males (2,900; 20 per 100,000 population).

- Some types of lymphoedema are related to cancer treatment and based on projected new cancer cases for 2022, around 4,100 people with breast cancer and between 1,600 and 5,100 people with melanoma of the skin will go on to develop secondary lymphoedema.

- Based on reporting covering 2020, around 2,500 people accessed state and territory compression garment subsidy schemes (excluding Queensland and Tasmania) with around 9,300 garments issued (excluding New South Wales and Tasmania).

Note, more work is needed to understand the prevalence in the Indigenous population.

No single data source is able to provide a holistic estimate of prevalence

The data sets with the most utility for calculating the prevalence of lymphoedema in Australia are the Australian Cancer Database, MedicineInsight and the National Integrated Health Services Information Analysis Asset (NIHSI-AA; includes admitted patient care, emergency department care, residential aged care, Medicare Benefits Schedule, Pharmaceutical Benefits Schedule and the national mortality register). A national primary care data set would encompass data from general practice as well as allied health professionals (such as physiotherapists) and would enhance the ability to identify people with lymphoedema in the community. Data linkage with NIHSI would enable the development of a representative estimate of the number of people in Australia living with lymphoedema. A National Primary Care Data Asset is in the early stages of development but will not be available for some time.

Compression garment subsidy scheme data could provide prevalence estimates

In July 2020, the then Minister for Health announced that Australians diagnosed with lymphoedema would have greater access to compression garments, thanks to ongoing funding from the Australian Government to complement the subsidisation of compression garments for people with lymphoedema under existing state and territory schemes. The introduction of these additional funds and the associated reporting to the Australian Government Department of Health and Aged Care provides an opportunity to collect information on the number of people in Australia living with lymphoedema. However, differences in how the states and territories administer the compression garment subsidy are likely to have had an impact on the data collected so far (discussed in Further investigation of compression garment data sources section).

> **Issues with the identification, diagnosis and treatment of lymphoedema**
>
> A critical issue is the misdiagnosis, or missing diagnosis of the condition due to lack of understanding and awareness of its presentation among medical practitioners. This leads to an under-diagnosis of the condition. Appropriate training and the provision of resources will help to facilitate early detection of the condition and improve outcomes for people living with lymphoedema.
>
> It is important to note that when attempting to identify people living with lymphoedema in available data sets there will be limitations relating to the definitions and terminology used. For example, most available data relate to lymphoedema as a result of cancer treatment and therefore underestimate the total prevalence of lymphoedema in Australia which needs to include primary lymphoedema and non-cancer-related lymphoedema.

1   Introduction

1.1 Purpose of this report

Chronic conditions are an ongoing cause of substantial ill health, disability and premature death, making them an important global, national and individual health concern (AIHW 2020a). Chronic conditions are generally characterised by their long-lasting and persistent effects.

Lymphoedema is the accumulation of excessive amounts of protein-rich fluid resulting in a permanent swelling of one or more regions of the body (ALA 2021). This is due to a mechanical failure of the lymphatic system and occurs when the demand for lymphatic drainage exceeds the capacity of the lymphatic circulation (ALA 2021).

> **Lymphoedema diagnoses are difficult, and misdiagnosis is common (Dylke 2022).**

Poor management of lymphoedema will have a negative impact on physical and psychosocial health, with pain and discomfort frequent symptoms. People with lymphoedema also have increased susceptibility to acute cellulitis, requiring hospitalisation and antibiotic therapy.

The purpose of this report is to assess the utility of a range of data sources to provide an estimate of the number of people in Australia living with lymphoedema. This report focuses on 6 key priority information areas:

- risk factors
- presence of condition
- treatment and management
- individual impact (quality of life and disability)
- population impact (expenditure, costs)
- demographics of the population/ study sample.

This work will provide the basis for future analytical reports describing the prevalence of lymphoedema and aligns with the vision of the National Strategic Framework for Chronic Conditions, particularly Objective 2: the provision of effective and appropriate care to support people with chronic conditions to optimise quality of life (AHMAC 2017).

1.2 Structure of this report

This report has 5 chapters:

- Chapter 1 outlines the purpose and structure of the report.
- Chapter 2 provides an introduction to lymphoedema, its causes, prevalence, diagnosis and treatment and management.
- Chapter 3 describes the scope and approach taken in this report, including the use of a framework to assess data sources for population health monitoring developed by the Australian Institute of Health and Welfare (AIHW 2014).
- Chapter 4 provides an assessment of available data sources that have the potential to be used to provide an estimate of the number of people in Australia living with lymphoedema using the framework described in Chapter 3.
- Chapter 5 provides an assessment of the most suitable data sources for estimating prevalence and potential avenues for future data development activities.

2 Lymphoedema

Lymphoedema is a condition where the accumulation of excessive amounts of protein-rich fluid in the tissue results in swelling of one or more regions of the body (ALA 2021). The condition more commonly affects the limb(s) although it may also involve the trunk, breast, head and neck or genital area (ALA 2021).

Lymphoedema is due to a failure of the lymphatic system and occurs when the demand for lymphatic drainage exceeds the capacity of the lymphatic circulation (ALA 2021).

Lymphoedema may arise due to a congenital malformation of the lymphatic system (primary lymphoedema) or due to damage, trauma or interference with the lymphatic vessels or nodes (secondary lymphoedema) (NSW Agency for Clinical Innovation 2018). Lymphoedema may develop at any time, some with primary lymphoedema presenting with it at birth. For secondary lymphoedema, it may develop within months of the damage or appear years later (ALA 2021).

> **What is the lymphatic system?**
>
> The lymphatic system is a network of vessels and nodes throughout the body that transports fluid (lymph) from the body tissues back to the bloodstream.
>
> The functions of the lymphatic system are to:
>
> - maintain the volume and protein concentration of the extracellular fluid in the body
> - to assist the immune system in destroying pathogens and removing waste products from the tissues.
>
> Source: ALA 2021.

Lymphatic system
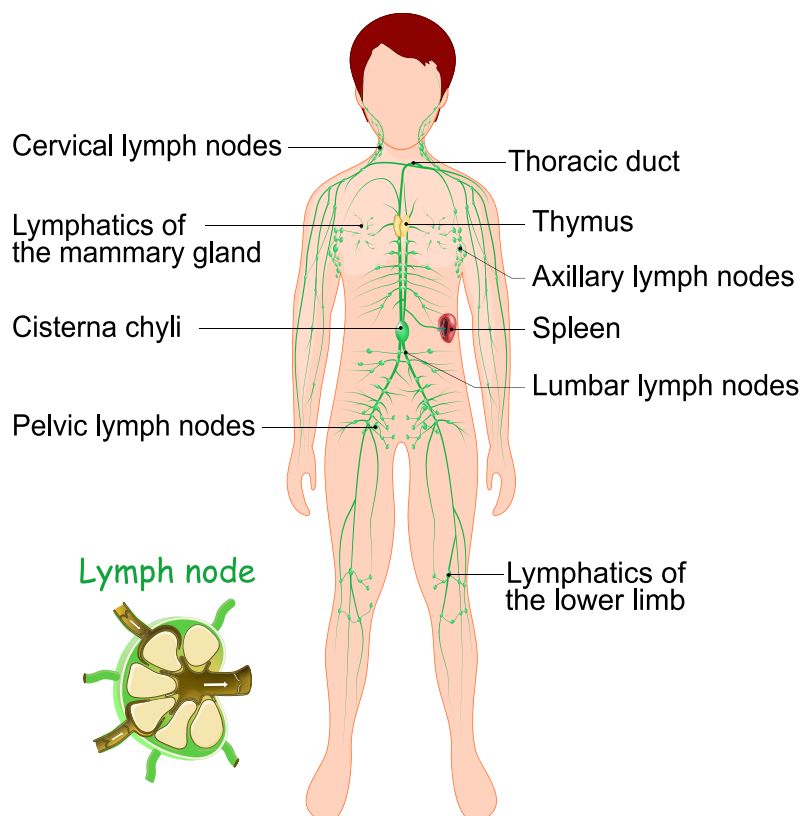
Lymphoedema is a chronic, progressive condition that left unmanaged will cause increasing morbidity for the individual (Casley-Smith 1995). While the condition can be managed, it requires significant time, effort and cost to prevent symptoms from worsening (Casley-Smith 1995). Lymphoedema can often cause pain and decreased limb movement and mobility, which can affect activities of daily living as well as prevent full engagement with the community and the workforce (NSW Agency for Clinical Innovation 2018). Lymphoedema may also affect a person's psychological health, resulting in negative body image, emotional disturbances, anxiety and depression, as well as social isolation (NSW Agency for Clinical Innovation 2018). Left untreated, people with lymphoedema are twice as likely to develop cellulitis requiring hospitalisation and intravenous antibiotic therapy (NSW Agency for Clinical Innovation 2018).

Lymphoedema is a chronic condition requiring lifelong care and management from a multidisciplinary team, which can be expensive. Costs for seeing practitioners and buying compression garments often add up, and time off work may be needed to attend appointments or manage infections (Cancer Council 2019). A study by Boyages and colleagues (2016) investigating perceived negative impact of breast cancer on respondents' work and career found that lymphoedema had an additional detrimental effect over and above breast cancer alone (Boyages et al. 2016). This impact of lymphoedema on work is incremental with increased severity of lymphoedema (Boyages et al. 2016).

2.1   Primary lymphoedema

Primary lymphoedema covers a variety of symptoms, of which chronic swelling is the primary or secondary concern. While work is ongoing, mutations to more than 10 genes have been identified, allowing a molecular diagnosis possible in about 26% of patients (Gordon et al. 2020). These genetic mutations may result in one or more of the following changes to the lymphatic system: hypoplasia of lymphatic vessels (a reduced number of lymphatic vessels), hyperplasia of lymphatic vessels (vessels are too large to be functional) or aplasia (absence) of some parts of the lymphatic system (ALA 2021). Primary lymphoedema may be present at any time from birth into adulthood depending on the underpinning genetic mutation (ALA 2021).

For those people who have a structural problem with the lymphatic system, the risk of developing secondary lymphoedema is likely higher if they have surgery or radiotherapy for cancer treatment or other surgeries (Rockson et al. 2019).

2.2   Secondary lymphoedema

Secondary lymphoedema is caused by damage to the lymphatic system, which prevents the lymph fluid from draining properly. Secondary lymphoedema can be classified into cancer treatment-related and non-cancer treatment-related lymphoedema.

Cancer treatment-related lymphoedema

Lymphoedema can occur following treatment for a number of cancers that typically involve the biopsy, dissection, or radiotherapy of the local lymph nodes. These cancers include breast, gynaecological, melanoma, head and neck and genito-urinary. Radiotherapy to lymph nodes and certain types of chemotherapy, particularly in combination with obesity, also increase the risk of developing lymphoedema (Rockson et al. 2019). It is important to note that, in addition to those listed above, any cancer that involves treatment that affects the lymphatic system increases the risk of developing lymphoedema.

Dissection (surgery to remove lymph nodes) is the clearest identified risk factor for the development of lymphoedema, with higher risk associated with greater lymph node removal (Rockson et al. 2019). Sentinel node biopsy is a less invasive procedure and reduces the risk of developing lymphoedema, though people can still develop lymphoedema following the procedure; for example, about 5% of patients treated for breast cancer using sentinel node biopsy will develop lymphoedema (DiSipio et al. 2013). Furthermore, if the biopsy is positive, subsequent treatment including radiotherapy or further surgery will affect lymphatic function (Rockson et al. 2019).

In Australia, recent studies indicate that non-cancer-related lymphoedema may be more common than cancer-related lymphoedema, at least in aged care and hospital settings (Cooper & Bagnall 2016; Gordon et al. 2019).

Non-cancer treatment-related lymphoedema

Any damage to the lymphatic system causes a lifelong risk of developing lymphoedema (ALA 2021). Secondary lymphoedema may also develop when one or more of the following occur (see Table 1):

Table 1: Classification of causes of secondary lymphoedema

Classification	Example
Trauma and tissue damage	• burns • varicose vein surgery • large wounds • scarring
Venous disease	• chronic venous insufficiency • venous ulceration • post-thrombotic syndrome • intravenous drug use
Infection	• cellulitis/ erysipelas • lymphadenitis • tuberculosis • filariasis
Inflammation	• rheumatoid arthritis • dermatitis • psoriasis • sarcoidosis • dermatosis with epidermal involvement
Endocrine disease	• pretibial myxoedema
Immobility and dependency	• dependency oedema • paralysis
Factitious	• self-harm
Other	• obesity • medication

Source: Lymphoedema Framework 2006.

2.3 Prevalence

There is currently no population-level prevalence estimate for the number of people in Australia living with lymphoedema. Using conservative estimates based on United Kingdom prevalence studies, the NSW Agency for Clinical Innovation estimates that there may be 70,000 people in Australia living with lymphoedema, though there is evidence that lymphoedema is under-reported and the actual prevalence may be higher (NSW Agency for Clinical Innovation 2018).

> **Primary lymphoedema is rare – at birth, about one person in every 6,000 will develop the condition (ALA 2021).**

A substantial amount of research has been undertaken to determine the prevalence of secondary lymphoedema among breast cancer patients. In 2008, the National Breast and Ovarian Cancer Centre (NBOCC) conducted an evidence review to describe the prevalence and incidence of secondary lymphoedema following treatment for cancer. The review concluded that lymphoedema is prevalent following treatment for breast cancer, affecting about 20% of survivors (NBOCC 2008). Prevalence studies involving systematic reviews and meta-analyses, large data sets and clinical populations provide further insight into the prevalence of the condition.

Study 1: DiSipio and colleagues (2013)

Systematic review and meta-analysis to determine the incidence of unilateral arm lymphoedema following breast cancer. Seventy-two studies met criteria for inclusion, with incidence estimated to be 21% when restricted to prospective cohort studies (DiSipio et al. 2013). Risk factors for the development of lymphoedema included extensive surgery (that is, axillary lymph node dissection, greater number of lymph nodes dissected, mastectomy), high body mass index, adjuvant therapy and low physical activity (DiSipio et al. 2013).

Study 2: Brayton and colleagues (2014)

In the United States of America, a retrospective analysis of health claims data from a large national private insurer was conducted to determine lymphoedema prevalence among cancer survivors. Prevalence among all cancer survivors increased from 0.95% in 2007 to 1.24% in 2013 (Brayton et al. 2014). It is important to note that prevalence for the types of cancers commonly associated with lymphoedema was not calculated in this study.

Study 3: Gordon and colleagues (2019)

In Australia using the LIMPRINT[1] framework, data was collected from 4 clinical populations: a residential care facility, a community-delivered aged care service, a hospital setting and a wound treatment centre. Of 222 participants, primary lymphoedema was reported in 7% and secondary lymphoedema reported in 43%. Of those with secondary lymphoedema, 93% of cases were non-cancer-related causes. Where non-cancer-related, venous problems were present in 80% of participants, and both immobility and obesity were reported to contribute to lymphoedema in 39% of participants (Gordon et al. 2019).

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1   The International Lymphoedema Framework (ILF) developed the Lymphoedema Impact Prevalence – International Lymphoedema Framework (LIMPRINT) project, an international study aimed at capturing the size and impact of chronic oedema in different countries and health services across the world. From 2014 to 2017, 9 countries with 40 sites have contributed to an international data set of over 13,000 patients.

2.4 Diagnosis

Lymphoedema may be diagnosed by a medical practitioner or lymphoedema health professional based on symptoms and past medical history and volume changes (Lymphoedema Association Australia 2022). As a part of the diagnosis process, a number of tests may be performed to determine the presence of swelling or lymphatic changes (NHS 2019):

Measuring limb volume

- Tape measure: used to measure the circumference of the limb, usually at regular intervals along the limb. These measurements can be compared with the same locations on the contralateral limb if unaffected or used to detect changes in size over time. Circumference measurements can also be used to calculate limb volume, using geometric formulas.

- Water displacement: Not widely used in Australia. Used to determine the volume of a limb. Can be compared with contralateral limb or used to detect changes in size over time.

- Perometry: an opto-electric device that measures circumference, which is converted into a limb volume.

Measuring extra-cellular fluid

- Bioimpedance spectroscopy – assesses the volume of extra-cellular fluid by passing a low frequency, harmless electrical current through the tissues. The resistance faced by the current is inversely proportional to the amount of extra-cellular fluid. Measurements are typically compared with the contralateral limb.

Imaging tests

- Imaging tests are not used routinely for the diagnosis of lymphoedema. Most-used imaging modalities are indocyanine green (ICG) with near infra-red fluorescence lymphatic imaging (NIRFLI), or lymphoscintigraphy, both of which can demonstrate the lymphatic pathways. Less frequently used imaging modalities include MRI, ultrasound and CT scans.

Issues with the diagnosis of lymphoedema

A critical issue when investigating the prevalence of lymphoedema is the misdiagnosis, or missing diagnosis of the condition due to lack of understanding and awareness of its presentation (Dylke 2022).

2.5 Treatment and management

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Case study: ACT Lymphoedema Service

In the Australian Capital Territory (ACT), the ACT Lymphoedema Service provides education and screening for those at risk of lymphoedema, as well as assessment, management and education for patients with lymphoedema or chronic oedema. The service accepts referrals from all health professionals.

The service operates as a hub and spoke model to provide accessible and equitable care to patients in the ACT and surrounding areas. Calvary Public Hospital Bruce is the hub of the service, and the spokes include 3 community health centres, and inpatient and home-based palliative care services. The Canberra Hospital is also a spoke, but provides management only for patients undergoing treatment in the Canberra Regional Cancer Centre. Across these locations, accredited lymphoedema therapists provide specialist care for patients, as well as conducting research, interprofessional education, and teaching for students.

The ACT Lymphoedema Service works collaboratively with private and regional practices from ACT and Southern NSW to manage complex patients effectively. Patients with lymphoedema accessing private practice may be able to use Medicare-funded chronic disease management plans prescribed by GPs to subsidise therapy.

Patients requiring specialist medical assessment can be referred to the Lymphoedema Clinic by a medical practitioner. This clinic is multidisciplinary, with both a medical practitioner and accredited lymphoedema physiotherapist completing assessment and appropriate referral for further assessment and management.

Occasions of service data

In the 2020–21 financial year, the Calvary Public Hospital Bruce Lymphoedema Service completed around 3,700 occasions of service across 940 individual patients. Of those patients, 8 (less than 1%) were children. These data include all patients seen across the Calvary Public Hospital Bruce Lymphoedema Service, including its 3 community clinics and palliative care service, but exclude data from patients accessing Canberra Hospital. It is likely these numbers are slightly lower than usual due to service limitations resulting from the COVID-19 pandemic.

For details on a prospective audit conducted in 2017 of all patients seen within the Calvary Public Hospital Bruce Lymphoedema Service, please see Appendix A, at: http://www.aihw.gov. au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

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While there is currently no cure for lymphoedema, it can be managed with appropriate care – often from a range of health professionals. With early intervention being the primary means of limiting the impact lymphoedema has on patients, identifying those at risk and early detection are important. The aims of lymphoedema treatment are to prevent progression of the condition, to reduce oedema and then maintain the improvement (ALA 2021). This includes the alleviation of associated symptoms,

prevention of infection and improvement of function and quality of life (ALA 2021). Patients should be referred to a qualified lymphoedema practitioner (medical practitioner, nurse or allied health professional with specialist training in the treatment and management of lymphoedema) for an individualised treatment program known as complex lymphoedema therapy (CLT). The treatments offered in CLT will vary depending on the stage of lymphoedema, the severity of symptoms and the financial and time resources of the patient. CLT consists of the following (Cancer Council 2019):

- **Compression therapy** – involves applying graduated pressure to reduce and contain swelling and soften any thickened tissue.
    - o Bandages are used to remove fluid from the swollen area and improve the shape and size of the swollen area. This intensive treatment often needs to be done regularly (multiple times per week) by a trained health care practitioner for a period of time (up to 6 weeks).
    - o Compression garments and wraps are used to maintain improvements in limb size and shape. Garments need to be fitted by a trained practitioner to ensure correct pressure is applied.
    - o Intermittent pneumatic compression pumps can also be used, as an adjunct to other forms of compression or by people unable to wear compression garments.
- **Skin care** – important in preventing infections and helps prevent skin changes.
- **Exercise** – regular physical activity such as walking and/ or resistance training may reduce the severity and symptoms of lymphoedema.
- **Massage therapy** – manual lymphatic drainage (MLD) involves mild pressure applied to the skin around the affected area to move fluid towards lymph pathways and nodes that are draining normally. Massage may also be helpful to soften fibrotic tissue.

A number of surgical treatment options are available and emerging if a patient's lymphoedema cannot be managed by the treatments mentioned above. Examples of surgical options include liposuction and lymphaticovenous anastomosis.

Lymphoedema Compression Garment Subsidy Scheme

In July 2020, the then Minister for Health, the Hon Greg Hunt, announced that Australians diagnosed with lymphoedema would have greater access to compression garments, thanks to additional funding from the Australian Government to complement the subsidisation of compression garments for people with lymphoedema under existing state and territory schemes.

The overarching aim of the scheme is to achieve increased access to compression garments for eligible patients in each state and territory. This is achieved by contributing directly to jurisdictional subsidy schemes, or by contributing to activities in jurisdictions that promote increased access to allied health professionals appropriately trained in the prescription of compression garments, or by contributing to activities that increase access to allied health professionals to enable the timely assessment of patients requiring compression garments. Further information on the scheme can be found here.

3   Data sources: assessment approach

3.1 Types of data sources

A number of data sources provide health information in Australia. Based on the various methods of data collection, the sources assessed in this report have been categorised into 1 of 7 categories:

- administrative data sources

- linked data sources

- survey-based data sources

- longitudinal surveys

- registry-based data sources

- general practice clinic information system (CIS) data extraction data sources

- other data sources.

The information in these data sources is obtained from individuals, government agencies and private and community organisations and health professionals. Information may also be collected continuously over many years to allow comprehensive analysis of chronic conditions or health service use over time, while once-off surveys provide a 'snapshot' at a particular point in time. A disease-monitoring system can include one or more of these data sources to inform the population health issue in question.

A description of each of these data sources, outlining their benefits and limitations, is provided at the beginning of each section in the report.

3.2 AIHW framework for assessing data sources

This report uses a modified version of the template from the AIHW's framework for assessing data sources for population health monitoring (AIHW 2014). Developed by the AIHW in 2014, the assessment framework is specifically tailored to assess population health data sources and can be used by other organisations undertaking similar projects. With a little modification, the framework could be applied to other subject areas when researching data potential.

As part of the assessment process, the framework identifies 3 steps:

1. collecting information about the data source

2. identifying the potential to inform key monitoring areas (using the template in Table 2)

3. assessing the quality of the data, using a modified version of the ABS Data Quality Framework (ABS 2009), to determine its 'fitnessforpurpose' by establishing its utility, strengths and limitations.

Detailed appraisals for each data source can be found in Appendix C at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

> **Data source considerations**
>
> It is important to note that when attempting to identify lymphoedema there will be limitations relating to definitions and terminology used. For example, lymphoedema is often coded as oedema or chronic oedema, which may or may not be lymphoedema. Furthermore, lymphoedema may be spelt as lymphedema (United States spelling).

Table 2: Data source information template for assessing data sources for population health monitoring

Full name of the survey or data collection	
Type of data source	For example: data source type (registry or administrative) and scope (national, state or regional).
Brief description	Brief outline of data source.
Purpose(s)	Main stated purpose or purposes of the data source.
Collection methodology	Key features of the collection methodology (administrative or survey) and data collection method (computer-assisted telephone interview, self-completion, administrative).
Scope (theoretical coverage of relevant population) and coverage (actual)	Population that is potentially covered, and actual population covered (response rate).
Geographic coverage	National, state or other.
Frequency/timing	Year(s) in which data have been collected.
Basic collection count	For example: treatment episodes or separations.
Size	Sample size or number of records in most recent reference period.
Collection management organisation	The organisation chiefly responsible for collecting and managing the data.
Further information	Where to go for further information.

Priority information areas	Risk factors	Conditions or medical interventions that are known risk factors for the condition.
	Presence of condition	Prevalence and incidence of chronic condition (whether the data source contains information on the health condition).
	Treatment and management	Pharmaceutical, procedures, allied health.
	Individual impact	Pain, disability, functioning, and social participation.
	Population impact	Carer impacts, impact of disease and other measures of expenditure/costs.
	Demographics of the study sample	For example: age, sex, location (remoteness and socioeconomic status can be generated from location in some cases), Indigenous status, marital status.

Source: AIHW 2019.

3.3 Scope

For a data source to be included in this report, it must include:

• Information in the key priority areas of 'risk factors' and/ or 'presence of condition' and 'demographics of the study sample'[2].

For the sake of timeliness, data sources must also have a collection period up to and including 2015. Sources deemed to be out of scope are shown in Appendix B, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

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2   An exception has been made for the Lymphoedema Compression Garment Subsidy Scheme data.

4 Assessment of available data sources

4.1 Administrative data sources

Administrative data sources contain information about the delivery of services, or a record of events, collected for historical or funding purposes.

These records are compiled into databases that are managed by various government agencies. The data may come from a large range of sources, such as deaths, hospital separations, Medicare payments or prescription pharmaceutical subsidy records. Although the primary purpose of administrative data collection is focused on various aspects of healthcare service delivery, these data can be used for secondary purposes reporting on various projects in isolation or with other data sources to inform policy and quality of care.

Because administrative data can capture almost all of the activity of a service, they are considered to have good coverage of a person or services at the national, state and territory or regional level. They are also suitable for generating time series because they are generally collected on an ongoing basis and reported frequently. However, these data sources have some limitations, such as issues with consistency and scope.

Eight data sources are discussed in this section and described in detail in Appendix C, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

1. Australian Prudential Regulation Authority (APRA) – private health insurance data

2. Department of Veterans' Affairs (DVA) client data

3. Medicare Benefits Schedule (MBS)

4. National Aged Care Data Clearing House (NACDC)

5. National Disability Insurance Scheme (NDIS)

6. National Hospital Morbidity Database (NHMD)

7. National Mortality Database (NMD)

8. National Non-Admitted Patient Care (episode level) Database (NNAP(el)D)

Table 3 provides an overview of the performance of each of the 8 data sources in relation to the 6 priority information areas.

Table 3: Administrative data source matrix

Name of data set	Some level of information available in priority information area					
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample
Australian Prudential Regulation Authority (APRA) - Private Health Insurance data	✓	✗	✓	✗	✓	✓
Department of Veterans' Affairs (DVA) client data	✓	✓	✓	?	✓	✓
Medicare Benefits Schedule (MBS)	✓	✗	✓	✗	✓	✓
The National Aged Care Data Clearinghouse (NACDC)	✓	✓	✓	✓	✓	✓
National Disability Insurance Scheme (NDIS)	✗	✓	✓	✓	✓	✓
National Hospital Morbidity Database (NHMD)	✓	✓	✓	✗	✗	✓
National Mortality Database (NMD)	✓	✓	✗	✓	✗	✓
National Non-Admitted Patient Care (episode level) Database (NNAP(el)D)	✓	✗	✓	✗	✗	✓

Seven of the 8 data sources contain information on risk factors for lymphoedema (**APRA**, **DVA**, **MBS**, **NACDC**, **NHMD**, **NMD** and **NNAP(el)D** data), which given the national coverage of these data is useful in determining cohorts at risk of developing lymphoedema (for example, people who have had lymph node excision procedures). However, these data sets cover particular populations (for example, people who are privately insured, DVA clients, older adults in aged care, outpatients and in-hospital medical treatment), which means the at-risk groups within specific populations only are able to be identified.

Five of the 8 sources include information on people diagnosed with lymphoedema (**DVA**, **NACDC**, **NDIS**, **NHMD** and **NMD** data), however characteristics of the data collections make it difficult to use these sources to estimate prevalence.

• **DVA** client data cover only those who receive support from DVA and may be serving or ex-serving members of t he Australian Defence Force (ADF), or the family, partner or dependant of a serving or ex-serving ADF member (AIHW 2018).

• The **NACDC** contains information on diagnosis of medical conditions, captured at Aged Care Assessment Program (ACAP) assessment or Aged Care Funding Instrument (ACFI) assessment.

From October 2022, ACFI has been replaced by Australian National Aged Care Classification (AN-ACC) (for more information see here). Note that these data sources do not capture lymphoedema accurately and only cover people in the aged care system.

- For the **NDIS**, a disability must be permanent and significant, affecting the ability to take part in everyday activities. This means that severe lymphoedema is accepted as a disability only when the condition is so severe that the individual cannot work or participate in normal activities. As a result, this source would capture only a very limited number of people who have the condition. Furthermore, approval providing access to compression garments was only introduced in October 2019.

- The **NHMD** would capture only people hospitalised for lymphoedema or those who have lymphoedema as an additional diagnosis, therefore potentially not including those with mild lymphoedema. In addition, the main reason for admission to hospital associated with lymphoedema would be cellulitis. Those with severe lymphoedema may also be managed outside of hospital. Furthermore, as the **NHMD** is event-based, it is not possible to use this data source to estimate prevalence without linkage. The inclusion of the **NHMD** in the National Integrated Health Systems Information Analysis Asset (NIHSI AA) enables **NHMD** data to become person-based, which assists in calculating prevalence (see Linked data sources).

- The **NMD** is not suitable for calculating prevalence as it captures those who have died as a result of lymphoedema as the underlying or associated cause of death.

Data snapshots

DVA client data

Based on DVA client data:

- Since 2011, 44 clients have liability accepted for a condition mentioning lymphoedema.

- In the 2020–21 financial year there were 3,929 treatment services for lymphoedema provided.

Notes

1. Lymphoedema includes: lymphoedema [broad], lower limb lymphoedema, upper limb lymphoedema and secondary lymphoedema [includes post-operative lymphoedema, metastatic melanoma with lymphoedema and other lymphoedema].

2. DVA clients who hold a Gold Card are eligible for any medical treatment, so the prevalence of claiming additional injuries/ illnesses after attaining a Gold Card status is very low. This may mean that clients are receiving treatment for lymphoedema without necessarily having it listed as an accepted condition.

3. Lymphoedema is not a commonly attributable condition to Defence service. The Repatriation Medical Authority currently has no Statement of Principle (SOP) for lymphoedema, nor is lymphoedema listed as a non-SOP condition.

Source: Data provided by DVA 2022.

NACDC

Based on the latest available results from the NACDC (ACFI), in 2020–21:

- Twenty-one per cent of all people in ACFI were assessed as requiring management of non-arthritic oedema OR deep vein thrombosis by the fitting and removal of compression garments and/ or compression bandages; OR chronic skin conditions by the application and removal of dry dressings and/ or protective bandaging.

- Two-thirds (67%) of these people were women.

- Two-thirds (65%) of these people were aged 85 and over.

Source: The National Aged Care Data Clearinghouse.

NDIS

Based on the latest available results from the NDIS (31 March 2022):

– In Victoria there were 40 participants with lymphoedema as a reported disability (primary or non-primary disability); in New South Wales there were 27 participants, and in Queensland there were 15 participants.

– The Australian Capital Territory, Queensland, South Australia, Tasmania and Western Australia each had fewer than 11 participants with lymphoedema as a reported disability.

Source: NDIS 2022.

NHMD

Based on the latest available results from the NHMD (2020–21):

– There were around 2,900 hospitalisations where lymphoedema was the principal diagnosis and 6,500 hospitalisations where lymphoedema was an additional diagnosis, comprising a total of 9,400 hospitalisations.

– The age-standardised rate of hospitalisations for lymphoedema as the principal or additional diagnosis was 30 per 100,000 population.

– The number and age-standardised rate of hospitalisations for lymphoedema was higher for females (6,500; 40 per 100,000 population) than for males (2,900; 20 per 100,000 population).

Notes

1. Rates have been age-standardised to the 2001 Australian Standard Population as at 30 June 2001. Age groups used for age standardisation are: 0-4, 5-9, 10-14, 15-19, 20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, 75-79, 80-84 and 85+.

2. Lymphoedema classified according to International Classification of Diseases, 10th Revision, Australian Modification (ICD-10-AM) codes I89.0 (lymphoedema not elsewhere classified), I97.2 (Postmastectomy lymphoedema syndrome).

3. Hospitalisations for which care type was reported as Newborn with no qualified days, and records for Hospital boarders and Posthumous organ procurement have been excluded.

Source: AIHW analysis of the AIHW National Hospital Morbidity Database.

NMD

Based on the latest available results from the NMD (2020):

– There were 68 deaths where lymphoedema was either the underlying or an associated cause of death.

– Lymphoedema as an underlying or associated cause of death was more common in females (85%; 58 deaths) than for males (15%; 10 deaths).

– All deaths occurred in those aged 55 and over, with almost two-thirds of deaths occurring in those aged 70 and over (87%; 59 deaths).

Notes

1. Lymphoedema classified according to International Classification of Diseases, 10th Revision (ICD-10) codes I89.0 (lymphoedema not elsewhere classified), I97.2 (Postmastectomy lymphoedema syndrome).

2. Cause of Death Unit Record File data are provided to the AIHW by the Registries of Births, Deaths and Marriages and the National Coronial Information System (managed by the Victorian Department of Justice) and include cause of death coded by the Australian Bureau of Statistics (ABS). The data are maintained by the AIHW in the National Mortality Database.

3. Year refers to year of registration of death. Deaths registered in 2020 are based on the preliminary version of cause of death data and subject to further revision by the ABS.

Source: AIHW analysis of the National Mortality Database.

4.2 Linked data sources

Data linkage is a method of bringing information from different sources together about the same person or entity to create a new, richer data set (Menzies Institute for Medical Research 2021). The linkage of information from disparate information sources enables the construction of chronological sequences of events and when used at the macro level provides valuable information for policy and research into the health and wellbeing of the population (Menzies Institute for Medical Research 2021). Data linkage assigns an identifying number to each person on a data set and then stores a set of links to all records for the person.

The linkages between administrative and research or clinical data sets provide an evidence base for policy makers and researchers to better understand population health and wellbeing and implement and evaluate service delivery and programs (Menzies Institute for Medical Research 2021).

Three data sources are discussed in this section and examined in Appendix C, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

1. Multi-Agency Data Integration Project (MADIP)

2. National Integrated Health Services Information (NIHSI) Analysis Asset

3. Victorian Integrated Non-Admitted Health (VINAH) data set

Table 4 provides an overview of the performance of each of the 4 linked data sources in relation to the 6 priority information areas.

Table 4: Linked data source matrix

Name of data set	Some level of information available in priority information area					
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample
Multi-Agency Data Integration Project (MADIP)	✓	✓	✓	✓	✓	✓
National Integrated Health Services Information (NIHSI) Analysis Asset	✓	✓	✓	✗	✓	✓
Victorian Integrated Non-Admitted Health (VINAH) minimum data set	✓	✓	✗	✗	✓	✓

All 3 linked data sources contain information on risk factors associated with the development of lymphoedema. Risk factor information in **MADIP** can be identified in the Survey of Disability, Ageing and Carers (SDAC), the National Health Survey (NHS) and the MBS. MBS risk factors relate to procedures that may lead to the development of secondary lymphoedema, whereas risk factors in SDAC and the NHS mainly relate to certain cancer types (SDAC and the NHS are discussed in detail in section 4.3 Survey-based data sources). In contrast, given the inclusion of admitted patient and MBS data in **NIHSI** there is a substantial number of risk factors for the development of secondary lymphoedema available within this data set. **VINAH** includes a number of risk factors for the

development of lymphoedema, including burns, cellulitis and chronic venous insufficiency as well as several cancers.

While **MADIP** has the ability to identify lymphoedema through the underlying cause of death variable, this will identify only those individuals who have died as a result of their lymphoedema. As seen in section 4.1 Administrative data sources, death from lymphoedema is a rare event.

NIHSI includes information relating to the diagnosis of lymphoedema derived from admitted patient data. Admitted patient data in **NIHSI** is aggregated by persons rather than hospital separations, enabling the calculation of the incidence/ prevalence of hospital-diagnosed lymphoedema. While **NIHSI** is national in scope, the admitted patient data for public hospitals currently does not include Western Australia or the Northern Territory. For private hospitals, **NIHSI** includes hospitals in Victoria, Queensland and the Australian Capital Territory. This somewhat limits its utility in providing an estimate of the prevalence of hospitalised lymphoedema in Australia.

VINAH includes lymphoedema as a health condition, however this data source captures only those seeking treatment for their lymphoedema in an outpatient setting and covers only patients in Victoria.

4.3 Survey-based data sources

Survey-based data sources collect health-related information through a population sample. Although some of the information collected can overlap with data obtained from administrative data sources, survey data include details relating to the experience of the individual (often through self-report methods) surveyed across a range of services and health conditions and can provide a greater depth of information than administrative data. Population surveys provide a valuable source of time series comparisons, provided the methodology, sampling and data quality are consistent for different survey periods.

Survey-based data sources can have limitations. The quality of the data from these sources depends on the response (willingness to participate), recall (ability to remember accurately) and the quality of the questions asked. Additionally, the sampling method for most population surveys is not designed to produce reliable estimates at regional levels nor for small, but important, subpopulations.

Three data sources are discussed in this section and examined in detail in Appendix C, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

1. Australian Bureau of Statistics (ABS) National Health Survey (NHS)

2. Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice

3. ABS Survey of Disability, Ageing and Carers Australia (SDAC)

Table 5 provides an overview of the performance of each of the data sources in relation to the 6 priority information areas.

Table 5: Survey-based data source matrix

Name of data set	Some level of information available in priority information area					
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample
Australian Bureau of Statistics (ABS) National Health Survey (NHS)	✓	✗	✓	✓	✗	✓
The Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice	✓	✓	✓	✗	✗	✓
ABS Survey of Disability, Ageing and Carers Australia (SDAC)	✓	✗	✓	✓	✓	✓

All 3 in-scope survey-based data sources contain information on risk factors for developing lymphoedema to varying degrees. While the **NHS** is the source most representative of the Australian population, the only risk factors available are skin, breast and genitourinary cancers and varicose veins. Similar risk factors are available in the **SDAC**. In contrast, the **BEACH** survey contains a range of medical conditions associated with the development of lymphoedema.

The **BEACH** survey is the only survey-based data source that contains lymphoedema as a diagnosis. Given that the scope of the **BEACH** survey is national and contains general practice encounter data it can be assumed to have good representativeness and coverage in terms of mild and possibly severe cases of lymphoedema. However, given that the survey was discontinued in 2016 the value of calculating a prevalence estimate from this source is somewhat limited. General Practice Clinic Information System data sources are appraised later in this report.

The **NHS** does contain prevalence estimates for oedema. Swelling in the body occurring following tissue trauma, wounds, acute infections, cardiac failure, blood vessel issues, thyroid, kidney or liver dysfunction, obesity and can sometimes be linked to medications (ALA 2021). In these cases, initial swelling is not caused by dysfunction in the lymphatic system and the condition is often referred to as 'oedema' (ALA 2021). However, there may be some impact on the lymphatic system drainage over time (National Lymphoedema Partnership 2015). Oedema of short duration is called 'acute' whereas oedema of longer duration (more than 12 weeks) is called 'chronic' (Moffatt et al. 2017). Lymphoedema may be coded incorrectly as oedema and so the prevalence of oedema could provide some relevant insights on the prevalence of lymphoedema although it is quite likely to overestimate.

Data snapshots

NHS

Based on the latest available results from the NHS (2020–21):

– The prevalence of oedema in Australia was 0.7% (an estimated 183,700 Australians).

– Oedema was more prevalent in the older age groups: for those aged 65 and over 3.0% reported experiencing oedema while in those aged 75 and over it was 4.5%.

Source: ABS 2022.

4.4 Longitudinal surveys

Longitudinal surveys involve repeated observations of the same sample over long periods of time. The length of the study may vary, with some longitudinal studies running for decades. Longitudinal studies are useful because they provide important data about changes experienced by individuals over time and allow for flexibility in the data collected at each time point. Another benefit of longitudinal data is that each variable does not need to be measured in each wave of the survey, because information about the individual is linked between waves–although this means that the variable will apply only in the waves in which it was collected. Longitudinal studies are also time consuming and can be expensive.

Three data sources are discussed in this section and examined in detail in Appendix C, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material:

1. 45 and Up Study

2. Australian Longitudinal Study on Women's Health (ALSWH)

3. Busselton Healthy Ageing Study (BHAS)

Table 6 provides an overview of the performance of each of the data sources in relation to the 6 priority information areas.

Table 6: Longitudinal data source matrix

Name of data set	Some level of information available in priority information area					
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample
45 and Up Study	✓	✓	✓	✓	✓	✓
Australian Longitudinal Study on Women's Health (ALSWH)	✓	✓	✓	✓	✓	✓
Busselton Health Study – The Busselton Healthy Aging Study (BHAS)	✓	✗	✗	✓	✗	✓

Each of the 3 longitudinal data sources contains some information on risk factors that can lead to the development of lymphoedema:

• The **45 and Up Study** has a number of items relating to whether participants have ever been diagnosed with the main types of cancers associated with lymphoedema (melanoma, breast and prostate cancers). This source also benefits from linkage with the MBS, which opens up a range of potential risk factors for the development of lymphoedema (most notably lymph node excision procedures). However, the scope of this source is restricted to people aged 45 and over living in NSW.

• Similarly, the **ALSWH** benefits from extensive data linkage, including linkage with the cancer registries, the MBS and admitted patient data, which enables the investigation of a wide range of risk factors associated with the development of lymphoedema in both hospital and out of hospital populations. The scope of the **ALSWH** is restricted to women.

- The **BHAS** contains a free-response item relating to type of cancer diagnosed, with responses including melanoma, cervical cancer, breast cancer and prostate cancer. Data from this source are restricted to people born between 1946 and 1964 living in the Busselton Shire of Western Australia.

Two of the 3 longitudinal data sources contain information on lymphoedema diagnoses, through responses to survey items and data linkage:

- The third wave of the **45 and Up Study** includes a survey item asking participants whether they have been diagnosed by a doctor as having lymphoedema.

- The **ALSWH** contains diagnoses of lymphoedema as a result of linkage with admitted patient data. As a result, this source is likely to capture only women with severe lymphoedema or other comorbidities that may have caused hospitalisation.

> ## Data snapshots
>
> **45 and Up Study**
>
> Based on the latest available results from the 45 and Up Study (Wave 3, 2018–2020):
>
> – Approximately 2,000 of the almost 100,000 participants (2%) in the survey reported having been told by a doctor that they had lymphoedema.
>
> Source: Sax Institute 2021.

4.5 Registry-based data sources

Registries systematically collect detailed information on persons with a certain disease or receiving a particular treatment. The data can be used to determine the incidence of an event or a disease, and the nature of an intervention or procedure. However, the data are specific to these events and sometimes do not include information from the entire general population.

It is difficult to generalise the results from some registries to the population as a whole. Further, findings derived from registry data may be limited in instances where full coverage of the relevant disease or treatment population is not obtained. For example, unless registries are supported by business processes, audits, mandatory data entry and/or by-product information from other technology, their complete coverage cannot be ensured.

One registry-based data source is discussed in this section and examined in detail in Appendix C, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

1. Australian Cancer Database (ACD)

Table 7 provides an overview of the performance of the ACD in relation to the 6 priority information areas.

Table 7: Registry-based data source matrix

Name of data set	Some level of information available in priority information area					
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample
Australian Cancer Database (ACD)	✓	✗	✗	✓	✗	✓

Cancer is a notifiable disease in all Australian states and territories so the **ACD** contains all diagnosed cases of cancer since 1982, providing complete coverage of the types of cancers that are commonly associated with the development of lymphoedema (see Cancer treatment-related lymphoedema). As a result, the **ACD** enables the identification of people at risk of developing cancer treatment-related lymphoedema but does not enable the identification of people at risk of developing non-cancer treatment-related lymphoedema.

While the **ACD** does not contain information relating to the diagnosis of lymphoedema, the prevalence of cancer-related lymphoedema can be estimated with reference to estimates from previous research, most notably the *Review of research evidence on secondary lymphoedema: incidence, prevention, risk factors and treatment* report where conservative estimates suggested that approximately 20% of breast, genitourinary, gynaecological, or melanoma survivors will experience secondary lymphoedema (NBOCC 2008). Specifically, the incidence of secondary lymphoedema associated with the type of cancer is estimated at: vulval cancer 36–47%, breast cancer 20%, cervical cancer 24% and melanoma 9–29% (NBOCC 2008).

Linkage of the **ACD** to other administrative or survey data sources could fill the presence of condition gap.

Data snapshot

ACD

Based on the estimated prevalence of cancer-related lymphoedema from the *Review of research evidence on secondary lymphoedema: incidence, prevention, risk factors and treatment* (NBOCC 2008) report, in 2022:

– Around 4,100 people with breast cancer will develop secondary lymphoedema (20% of 20,600 cases).

– Between 1,600 and 5,100 people with melanoma of the skin will develop secondary lymphoedema (9% to 29% of 17,800 cases).

– Between 150 and 200 women with vulval cancer will develop secondary lymphoedema (36% to 47% of 420 cases).

– Around 200 women with cervical cancer will develop secondary lymphoedema (24% of 940 cases).

Source: AIHW 2022.

4.6 General practice Clinic Information System (CIS) data extraction data sources

General practitioners play an important role in the management of the health and wellbeing of Australians. They are often the first point of contact for the diagnosis and management of health-related issues. There is currently no nationally consistent primary health care data collection to monitor the provision of care by GPs in Australia. There are, however, data sources that capture information from participating general practices CIS. The vast majority of Australian general practices now use CIS tools, which have become vital in the delivery of safe and high-quality health care and good practice management (RACGP 2018). Some of the core functions of general practice CIS (RACGP 2018) are to:

- manage patient personal details and demographic information

- record health care history, social history, risk factors and allergies

- record, track and support follow-up reminders for preventive medicine and recalls for ongoing care

- manage medications and generate electronic transfer of prescriptions

- create electronic referrals and receive electronic reports, including specialist letters and discharge summaries

- create electronic diagnostic orders and receive laboratory and radiology reports.

Two CIS data extraction data sources are discussed in this section and examined in Appendix C, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

1. MedicineInsight Data

2. POLAR Data

Table 8 provides an overview of the performance of each of the 2 CIS data extraction data sources in relation to the 6 priority information areas.

Table 8: General practice CIS data extraction data source matrix

Name of data set	Some level of information available in priority information area					
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample
MedicineInsight Data	✓	✓	✓	✗	✓	✓
POLAR Data	✓	✓	✓	✗	✓	✓

Both of these data sources contain information on risk factors for developing lymphoedema, including diagnoses of conditions that are associated with lymphoedema. These data sources also contain diagnoses of lymphoedema, however geographic coverage differs between the two. In 2019–20 **MedicineInsight** data covered 5.6% of Australian General Practices and 11% of Australian GPs, with coverage across states and territories similar to national coverage (NPS MedicineWise 2022). Approximately 2.5 million patients were seen at least once by GPs in the participating practices, representing 11% of all patients seen by GPs nationally (NPS MedicineWise 2022). As a result, prevalence estimates calculated from this data source can be assumed to have good

representation of the Australian population. Geographic coverage for **POLAR** data extends across 5 Primary Health Networks (PHNs) – Central and Eastern Sydney, Gippsland, Eastern Melbourne, South Eastern Melbourne and South Western Sydney. As a result, the representativeness of prevalence estimates calculated from this source would be influenced by characteristics associated with these populations (for example, potentially higher socio-economic status; access to health care).

It is also important to consider that patients with lymphoedema may have been diagnosed in other care settings and may not have had their diagnosis recorded in the GP system, thus they will not be captured by CIS data extraction data sources.

Data snapshots

POLAR

Based on data from the POLAR platform:

– Lymphoedema was an existing diagnosis among 6,259 patients who visited a practice at least once during 2020, equating to a prevalence of 0.2%[3].

– Most of these patients were female (82%; 5,140 patients).

– Two-thirds of these patients were aged 65 and over (64%, 3,980 patients).

Source: POLAR (includes Central and Eastern Sydney, Eastern Melbourne, Gippsland, South Eastern Melbourne, South Western Sydney PHNs).

4.7 Other data sources

Data can also be derived from sources other than the types already addressed in this report. Health intervention programs often involve some form of reporting to the funder of the program as a way of assessing the success of the program. These data could be the number of people who have accessed a service, the cost of the service and/ or the number of organisations that have signed up to provide a particular service.

One data source is discussed in this section and examined in Appendix E, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

1. Lymphoedema Compression Garment Subsidy Scheme reporting data

Table 9 provides an overview of this source in relation to the 6 priority information areas.

Table 9: Other data source matrix

Name of data set	Some level of information available in priority information area					
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample
Lymphoedema Compression Garment Subsidy Scheme reporting data	✘	✓	✓	✘	✓	✘

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3   Calculated from the study population of 3.6 million unique RACGP Active Patients with a visit in 2020. RACGP Active Patients are defined as having had 3 or more visits in 2 years.

Each state and territory has an agreement with the Australian Government in order to receive supplementary funding toward their scheme (for state and territory scheme details see Appendix D, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material). As part of these agreements, states and territories provide annual performance reports to the Department of Health and Aged Care. Reporting for the scheme, where possible, includes:

- how many individuals have accessed the scheme in any given reporting period
- how many garments have been provided under the scheme
- training activities to assist with operation of the scheme, such as development of training modules, or numbers of health professionals accessing training
- the total cost of the scheme (garments provided under the scheme, and administration of the scheme), and
- any other data or information relating to activities conducted under the scheme.

As previously mentioned, the overarching aim of the scheme is to achieve increased access to compression garments for eligible patients in each state and territory. States and territories are using the Australian Government funding in different ways to achieve this aim, including by:

- contributing directly to jurisdictional subsidy schemes
- contributing to activities in jurisdictions that promote increased access to allied health professionals appropriately trained in the prescription of compression garments
- contributing to activities that increase access to allied health professionals to enable the timely assessment of patients requiring compression garments.

In addition, the states and territories each have varying eligibility requirements to access subsidised compression garments via their schemes. Details of how each state and territory used funding from the scheme in 2020 is available in Appendix D, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material.

Given the nature of the scheme, presence of condition can be inferred – most state and territories require a diagnosis of lymphoedema for patients to access the scheme.

Data snapshots

Lymphoedema Compression Garment Subsidy Scheme

Based on data from the first report covering 2020[4]:

- Around 2,500 people accessed the scheme (this does not include Queensland or Tasmania).
- Around 9,300 garments were issued (this does not include New South Wales or Tasmania).
- There were around 2,000 new referrals to the scheme (this does not include Queensland or Tasmania).

Note: Queensland and New South Wales are large states and absence of their data would affect these numbers significantly.

Source: Lymphoedema Compression Garment Subsidy Scheme 2021.

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4   Data for South Australia covers the period 14 July to 31 December; data for Western Australia covers the period 11 Jan 2021 to 31 March 2021. Data for Tasmania is not included.

5 Discussion

This scoping report assesses the utility of a range of available data sources in determining an estimate of the number of people in Australia living with lymphoedema. This chapter provides a comparative assessment of the available data sources, identifies gaps in the available data and identifies future opportunities for data development.

In chapter 4 a number of data sources within 7 categories were assessed for their utility in determining an estimate of the incidence/ prevalence of lymphoedema.

> Following an appraisal of each in-scope data source it is evident that not one individual source is able to provide a holistic estimate of the number of Australians living with lymphoedema, particularly for those with non-cancer-related lymphoedema. The data sets with the most utility for calculating the prevalence of lymphoedema in Australia are the Australian Cancer Database, MedicineInsight and the National Integrated Health Services Information Analysis Asset.

5.1 Data deficiencies and gaps

Following the appraisal of each in-scope data source included in this report, a number of data gaps have been identified. The main deficiency is that there is no single data source that has the ability to provide an estimate of all Australians living with lymphoedema, due to factors associated with scope, the purpose of data collections and the awareness/ recognition of lymphoedema as a medical condition.

Population scope

The **NHS** and **MADIP** are the only data sources with a nationally representative Australian population. Unfortunately, the **NHS** is not able to measure the number of people living with lymphoedema due to it not being included in the list of medical conditions, while lymphoedema is only potentially available in **MADIP** via underlying cause of death which is rare. All other data sources cover specific populations only – for example in-hospital patients, privately insured patients, people with cancer, women and persons aged 45 and over living in NSW. While estimates can potentially be extrapolated from the available data sources to the Australian population, it would be difficult to ascertain how accurate these estimates are.

Purpose of data sources

With the exception of a few sources (the **NHS**, the **45 and Up Study** and the **ALSWH**) the majority of the in-scope data sources were not designed to measure the prevalence of medical conditions. While the **NHMD, BEACH** and the general practice CIS data sources contain information on medically diagnosed lymphoedema, it is difficult to derive prevalence estimates from these sources. In particular, the **NHMD** is based on hospital separations rather than individual patients, which prevents the calculation of prevalence. While it may be possible to calculate prevalence from **MedicineInsight** and **POLAR**, it is important to remember that this is not the primary aim of these systems, which are designed to aid in the delivery of safe and high-quality health care and good practice management.

Awareness and recognition of lymphoedema

There is a lack of awareness of lymphoedema among medical practitioners, leading to under-diagnosis of the condition. Appropriate training and the provision of resources will help to facilitate early detection of the condition and improve outcomes for people living with lymphoedema.

While medically diagnosed lymphoedema is available in some administrative data sets and the general practice CISs, it is not included as a medical condition in any of the survey-based data sources and is included in two of the longitudinal data sources (**45 and Up Study, and the ALWHS**). This is potentially the result of a lack of awareness of lymphoedema among medical practitioners, leading to the under-diagnosis of the condition. This under-diagnosis is likely to correspond to a significant under-representation of the condition in data sources. By raising awareness of lymphoedema among medical practitioners, providing training and resources to medical practitioners and correspondingly increasing its representation in relevant data sources, surveys such as the **NHS** may include the condition, which would enable the calculation of prevalence. However, large-scale national surveys are not well equipped to capture data to estimate lower prevalence conditions due to issues associated with high sampling variability and high relative standard errors/ margins of error, as well as a lack of power to detect differences between groups. A targeted survey is likely to be a better method by which to estimate the prevalence of lymphoedema.

Lymphoedema representation in the MBS

During the recent Medicare Benefits Schedule Taskforce Review, submissions to include an MBS item for complex lymphoedema therapy (CLT) were put forward. The inclusion of this item would enable the identification of people with lymphoedema in the community as the therapy would be provided most likely through allied health services (for example, physiotherapists, occupational therapists) and nurses. The Taskforce did not recommend the creation of such an item as the Medical Services Advisory Committee (MSAC) is the appropriate channel for the creation of new items. However, it should be noted that the MBS is not designed for data collection, and items need to relate to medical services.

5.2 Future opportunities and next steps

There are a number of ways in which data relating to Australians with lymphoedema could be improved. These include using current data sources via data linkage, establishing a nationally representative primary care data set and developing a targeted survey and a lymphoedema register. Improvement in data relating to lymphoedema also depends on the accurate diagnosis of the condition and the use of consistent terminology for the condition.

Estimating prevalence using identified data sources

The first step can be to use **NIHSI**, **MedicineInsight** and the **ACD** to estimate the prevalence of lymphoedema within the admitted patient, general practice, and cancer populations. Future reports can potentially perform analysis on national primary care data to obtain a nationally representative estimate of the number of people in Australia living with lymphoedema within the primary care population. Data linkage with NIHSI would enable the development of a representative estimate of the number of people in Australia living with lymphoedema.

The information contained in the **ACD** could be enhanced by linkage to other administrative and/ or survey data sets. In particular, linkage to data sources such as the **NHMD** would enable the identification of lymphoedema in people with the specific types of cancers. This would provide a more accurate estimate of the prevalence of cancer-related secondary lymphoedema in Australia but would miss any lymphoedema incidence not related to cancer treatment. Development work is under way within the AIHW to create an enduring linked data asset that includes **ACD**, **MBS**, **PBS**, deaths and hospital inpatient data.

Primary care data

There is no national primary care data set in Australia. A national primary care data set would encompass data from general practice as well as allied health professionals (such as physiotherapists). Work is currently under way to develop a National Primary Care Data Asset (Data Asset) within the AIHW. The vision for and value of the Data Asset is that it will facilitate understanding of the primary health care patient journey, fill primary care data and information gaps and be an accessible and value-added information and evidence base for researchers, policy makers and the public. To achieve this vision and realise its value, the Data Asset will enable data linkage, analysis and outcome reporting, across the breadth of primary health care data and practice and between the primary, secondary and aged care sectors. The Data Asset is in the early stages of development and will not be available for linkage at a national level for some time. Improvements to GP clinic information system software would be required to accurately capture lymphoedema in a National Primary Care Data Asset.

The development of a targeted survey

Given that inclusion in a large-scale national survey such as the NHS is unlikely to produce reliable estimates of the prevalence of lymphoedema, a smaller scale targeted survey has the capacity to provide further insights on the prevalence of the condition. One such survey could be a national survey of physiotherapists working in the hospital outpatient setting and community specifically designed to collect the number of patients being treated for lymphoedema. A survey such as this could provide a national prevalence estimate of people diagnosed with and being treated for lymphoedema.

A targeted survey could involve state and territory cancer registries recruiting people who have cancer types where treatment is associated with the development of secondary lymphoedema. These individuals could be contacted to participate in a voluntary survey to determine whether they developed secondary lymphoedema following the treatment for their cancer. The Australian Mesothelioma Register (AMR) uses a similar approach. For more information see Mesothelioma in Australia 2021: methodology paper (aihw.gov.au) (AIHW 2023).

Lymphoedema register

The primary purpose of a condition/ disease registry is to collect diagnostic details on patients with specific diseases or conditions (Monash University 2021). A lymphoedema register would capture the information needed to make reliable estimates of incidence/ prevalence, however disease registers are expensive to operate and are often reserved for conditions with the greatest burden of disease and cost to the Australian health system and/or greatest variation in care and outcomes, such as cancer. Disease registers work best when the condition is notifiable and must be reported as directed by legislation. Disease registers can also be successful when incentives for participation are offered. An example is the National Diabetes Services Scheme (NDSS) data which offers people living with type 1, type 2, gestational or 'other' diabetes access to information, subsidised diabetes products from community pharmacies, education, group sessions and support programs (for more information see About the NDSS).

There are also international examples of existing lymphoedema registers. For example, see The International Lymphatic Disease and Lymphedema Patient Registry & Biorepository (Lymphatic Education & Research Network 2023).

Another option would be to reinstate the Australasian Lymphology Association patient registry (ANZLoR). The primary goal of the lymphoedema registry (ANZLoR) was to help those living with lymphoedema to receive better care and support through improved services and resources (ALA 2023). Improvements to ANZLoR could include investment in the infrastructure required to create and maintain the register as well as participant permission to link ANZLoR data to other data sources. As ANZLoR was voluntary, raising awareness among lymphoedema medical and allied health professionals would ensure patients were encouraged to participate in the register. Modifications to ANZLoR to improve participation may also include incentives to patients in the form of access to subsidised compression garments. Modelling this register on other disease registers used to monitor the incidence and prevalence of disease in Australia may provide insight into best practice for recruiting patients.

Further investigation of compression garment data sources

The Lymphoedema Compression Garment Subsidy Scheme presents a unique opportunity to collect information on the number of people living with lymphoedema by state and territory. Given that the scheme has varying commencement dates according to the state or territory, one as recent as 2020, more time may be needed for people with lymphoedema to become aware of and access the schemes. As a result, it may be worth revisiting this data source in a few years' time. One potential drawback of this source is the differing eligibility requirements between the states and territories (See Appendix D, at: http://www.aihw.gov.au/reports/chronic-disease/prevalence-of-lymphoedema-in-australia/related-material).

Data from compression garment suppliers and manufacturers also presents an opportunity to gain further insight into those in Australia living with lymphoedema. As compression garments are the mainstay of lymphoedema treatment, this source could potentially provide complete coverage of

those living with lymphoedema, from mild to severe. Whether access to data from compression garment manufacturers is possible, as well as the quality of these data, is worthy of further investigation.

Introduction of an MBS item for Complex Lymphoedema Therapy

Having an item in the MBS for Complex Lymphoedema Therapy (CLT) could significantly enhance the identification of people living with lymphoedema as well as quantify the services for CLT in Australia. However, the purpose of the MBS is to provide a patient rebate for clinically relevant services, and it is not designed or intended to collect diagnostic information.

Other data sources

While the purpose of this report was to assess the utility of available data sources, there are 3 further potential sources beyond those explored that are worthy of investigation.

Data sources capturing information on children living with lymphoedema are limited. Some hospitals (such as The Children's Hospital, Westmead and the Queensland Children's Hospital, Brisbane) provide compression garments to children up to ages 16 to 18. There is a potential opportunity to capture this information for monitoring purposes.

Cellulitis, a bacterial skin infection that people with lymphoedema are at a higher risk of contracting, is classified as a potentially preventable hospitalisation (PPH). PPH are specific hospital admissions that potentially could have been prevented by timely and adequate health care in the community and are a proxy measure of primary care effectiveness (AIHW 2020b). Given growing evidence that lymphoedema is a strong risk factor for cellulitis (Webb et al. 2020), PPH data for cellulitis may provide insights into the impact of lymphoedema. Similarly, emergency department data on people presenting with cellulitis may also provide insights into the impact of living with lymphoedema.

Acknowledgments

Abbreviations

ABS	Australian Bureau of Statistics
ABDS	Australian Burden of Disease Study
ACAP	Aged Care Assessment Program
ACD	Australian Cancer Database
ACFI	Aged Care Funding Instrument
ACSQHC	Australian Commission on Safety and Quality in Health Care
ADF	Australian Defence Force
AIHW	Australian Institute of Health and Welfare
ALA	Australasian Lymphology Association
ALSWH	Australian Longitudinal Study on Women's Health
AMR	Australian Mesothelioma Register
AN-ACC	Australian National Aged Care Classification
ANZLoR	Australasian Lymphology Association patient registry
APEG	Australasian Paediatric Endocrine Groups
APRA	Australian Prudential Regulation Authority
BEACH	Bettering the Evaluation and Care of Health
BHAS	Busselton Healthy Ageing Study
BMI	Body Mass Index
CHAMP	Concord Health and Ageing in Men Project
CIS	Clinic Information System
CLT	complex lymphoedema therapy
DACA	Disability, Ageing and Carers, Australia
DSP	Disability Support Pension
DVA	Department of Veterans' Affairs
GP	general practitioner
HILDA	Household, Income and Labour Dynamics in Australia Survey
ICD-10-AM	International Classification of Diseases, 10th Revision, Australian Modification
ICG	indocyanine green
ISL	International Society of Lymphology
LGA	Local Government Area
MADIP	Multi-Agency Data Integration Project
MBS	Medicare Benefits Schedule
MLD	manual lymphatic drainage

NACDC	The National Aged Care Data Clearinghouse
NDR	National Diabetes Register
NDSS	National Diabetes Services Scheme
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NHMD	National Hospital Morbidity Database
NHS	National Health Survey
NIHSI	National Integrated Health Services Information
NIHSI-AA	National Integrated Health Services Information Analysis Asset
NIRFLI	near infra-red fluorescence lymphatic imaging
NMD	National Mortality Database
NNAP(el)D	National Non-Admitted Patient Care (episode level) Database
NWAHS	North West Adelaide Health Study
PHNs	Primary Health Networks
POLAR	Population Level Analysis & Reporting
PPH	potentially preventable hospitalisation
SA2	Statistical Area Level 2
SDAC	Survey of Disability, Ageing and Carers
SOP	Statement of Principle
VINAH	Victorian Integrated Non-Admitted Health

Glossary

aplasia: Occurs when there is an absence of some parts of the lymphatic system.

cellulitis: Cellulitis is a skin infection usually caused by bacteria.

chronic conditions: A diverse group of diseases/conditions, such as heart disease, cancer and arthritis, which tend to be long lasting and persistent in their symptoms or development. Although these features also apply to some communicable diseases (infectious diseases), the term is usually confined to non-communicable diseases.

contralateral limb: occurring on or acting in conjunction with a part on the opposite side of the body.

hyperplasia: Occurs when lymphatic vessels are too large to be functional.

lipoedema: Lipoedema usually occurs in women, and results in excessive fat deposition at times of hormonal change, such as puberty or pregnancy.

lymphatic system: An extensive network of vessels, nodes, and ducts that pass through almost all bodily tissues. It allows the circulation of a fluid called lymph through the body in a similar way to blood.

lymphoedema: Lymphoedema is due to a failure of the lymphatic system and occurs when the demand for lymphatic drainage exceeds the capacity of the lymphatic circulation.

lymphoscintigraphy: A method used to check the lymph system for disease.

misdiagnosis: An incorrect diagnosis.

oedema: Oedema (spelt "edema" in some countries) is swelling caused by the accumulation of fluid in a particular part of the body.

primary lymphoedema: Occurs when the demand for lymphatic drainage exceeds the capacity of the lymphatic system and may develop due to a congenital malformation in the lymphatic system.

principal diagnosis: The diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital.

secondary lymphoedema: Occurs when there is damage to the lymphatic vessels or nodes.

sentinel node biopsy: A procedure in which the sentinel lymph node is identified, removed, and examined to determine whether cancer cells are present.

Data sources

ABS National Health Survey (NHS)

The National Health Survey, run by the ABS, collects data on the health of Australians including health conditions, health risk factors and demographic and socioeconomic information. It is part of a series of national health surveys by the ABS since 1977. Further information on the NHS can be found here.

Australian Cancer Database (ACD)

The ACD contains data about all new cases of cancer diagnosed in Australia since 1982, excluding basal and squamous cell carcinomas of the skin. Cancer is a notifiable disease in all Australian states and territories. Relevant legislation requires certain individuals and organisations to notify all new cases of cancer to the jurisdiction's central cancer registry. These registries supply data annually to the AIHW, which cleans and standardises it and notifies the registries of interstate duplicates. Further information on the ACD can be found here.

Department of Veterans' Affairs (DVA)

The Department of Veterans' Affairs (DVA) takes a proactive approach in commissioning research to build an effective evidence base that supports the health and wellbeing needs of Australia's veterans. DVA holds a range of data that is valued for its scientific research potential and increasingly for internal data analytics projects. This includes both administrative data related to client services and health study data collected as part of commissioned research studies. Further information on DVA can be found here.

Lymphoedema Compression Garment Subsidy Scheme

In July 2020, the then Minister for Health Greg Hunt announced that Australians diagnosed with lymphoedema would have greater access to compression garments, thanks to additional funding from the Australian Government to complement the subsidisation of compression garments for people with lymphoedema under existing state and territory schemes.

The overarching aim of the scheme is to achieve increased access to compression garments for eligible patients in each state and territory. This is achieved by contributing directly to jurisdictional subsidy schemes, or by contributing to activities in jurisdictions that promote increased access to allied health professionals appropriately trained in the prescription of compression garments, or by contributing to activities that increase access to allied health professionals to enable the timely assessment of patients requiring compression garments. Further information on the scheme can be found here.

National Hospital Morbidity Database (NHMD)

The NHMD is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian public and private hospitals. The scope of the NHMD is episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, correctional authorities and in Australia's offshore territories may also be included. The hospital separations data do not include episodes of non-admitted patient care provided in outpatient clinics or emergency departments. Patients in these settings may be admitted subsequently, with the care provided to them as admitted patients being included in the NHMD. Further information on the NHMD can be found here.

National Mortality Database (NMD)

The AIHW NMD contains cause of death information provided by the registries of births, deaths and marriages and the National Coronial Information System, and coded by the ABS, for deaths since 1964. Registration of deaths is the responsibility of each state and territory's Registry of Births, Deaths and Marriages. These data are then collated and coded by the ABS and are maintained at the AIHW in the NMD. The AIHW uses these data in various reporting activities to monitor the health of Australians and to inform policy and planning. Summaries of causes of death, including trends and deaths among different population groups, can be derived from this long-term data set. Further information on the NMD can be found here.

Population Level Analysis & Reporting (POLAR)

POLAR is a business intelligence tool that uses extracted data from a clinical and billing software program and can be used by practice staff and GPs. Practices can use POLAR for quality improvement, to support business development and help provide better patient-centred care. More information about POLAR can be found here.

The National Aged Care Data Clearinghouse (NACDC)

The National Aged Care Data Clearinghouse (NACDC) is an independent and central repository of national aged care data. It brings together information on people receiving aged care and the services and organisations providing care. The NACDC comprises more than 110 tables in complex relational databases. Most of these relate to government-funded aged care programs operating under the Aged Care Act 1997. The NACDC includes activity data for aged care assessments, home support, home care, transition care and residential aged care. It also contains other data sources related to quality indicators for residential aged care and consumer experience in residential aged care. Most of the activity data is refreshed annually with data from the Department of Health and Aged Care's Data Warehouse. Data for quality indicators are supplied quarterly. Other data sources are updated on a less regular or ad hoc basis. Further information on the NACDC can be found here.

45 and Up Study

The 45 and Up Study is owned and managed by the Sax Institute, in close collaboration with its major partner Cancer Council NSW along with other partners the Heart Foundation and the NSW Ministry of Health. The study has been following more than 250,000 people aged over 45 in NSW since 2005 and has made important contributions to our understanding of a wide range of key public health issues ranging from heart disease and physical activity to cancer and COVID-19.

The 45 and Up Study is Australia's largest ongoing study of health and ageing and has already been used by more than 800 researchers to explore a broad range of health issues including diabetes, cancer, obesity, mental health, environmental health, and health service access and equity. Further information on the 45 and Up Study can be found here.

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List of tables

Lymphoedema is a condition where the accumulation of excessive amounts of protein-rich fluid in the tissue results in swelling of one or more regions of the body. The purpose of this scoping study is to assess the utility of available data sources in determining an estimate of the number of Australian's living with lymphoedema. This report provides the basis for future analytical reports describing the prevalence of lymphoedema.

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