



Australian Government

**Australian Institute of
Health and Welfare**

Towards an estimate of the prevalence of lymphoedema in Australia: a data source scoping report 2023

Appendix

The logo for the Australian Institute of Health and Welfare (AIHW), consisting of the letters 'AIHW' in a bold, sans-serif font. Each letter is a different color: 'A' is teal, 'I' is green, 'H' is blue, and 'W' is purple.

AIHW

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Appendix A: Calvary Public Hospital Lymphoedema Service prospective audit, 2017

In 2017, the Calvary Public Hospital Bruce Lymphoedema Service completed a prospective audit of all patients seen within the clinic over a 3-month period. For each patient, gender, height and weight, and location, cause and severity of oedema was recorded. Children and patients who could not access the scales due to being wheelchair bound, having a mobility impairment or being severely obese were excluded. The audit included 213 participants, of whom 78% were female. Of the participants, 84% were aged 50 or over and 10% were aged 80 or more. The identified cause of oedema was primary in 10%, secondary in 89% and lipoedema in 1%. Of the participants with secondary lymphoedema, 67% were cancer related. For participants with non-cancer-related secondary lymphoedema, the most commonly identified contributing factors were obesity (29%), venous disease (23%) and surgery or trauma (23%). Of all the participants, lymphoedema was located in the lower limbs for 57%, the upper limb for 39%, the breast for 3% and the head and neck for 2% with some patients having swelling in more than one location. Using the International Society of Lymphology (ISL) Lymphoedema Staging, the stage of lymphoedema was 0 for 6%, 1 for 9%, 2 for 62%, and 3 for 8%, with the remaining 15% being seen for prophylactic monitoring. Only 14% of patients were classified as being in the healthy weight bracket (BMI 18.5–24.9), with 0.5% being classified as underweight (BMI <18.5). Just over 60% of patients were obese (BMI ≥30), 14% were obese class II (BMI 35–39.9) and 26% were obese class III (BMI >40). Prevalence of obesity (BMI ≥30) differed considerably between the primary, cancer-related and non-cancer-related lymphoedema groups, being 66%, 47% and 85% respectively.

Appendix B: Out of scope data sources

Type and name of data set	Some level of information available in priority information area						Comments
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample	
Administrative							
Disability Support Pension (DSP)	x	x	x	✓	✓	✓	Disaggregation beyond the 20 conditions are not provided for data requests.
Pharmaceutical Benefits Scheme	x	x	x	x	✓	✓	Paroven (no evidence of efficacy), not in the PBS.
AIHW Disease Expenditure Database	✓	x	x	x	✓	✓	Collection is about expenditure on health.
National Hospital Cost data collection	x	x	x	x	?	✓	Collection is about hospital expenditure.
Survey-based							
ABS General Social Survey	x	x	x	✓	✓	✓	No information on risk factors or presence of condition.
Longitudinal							
Household, Income and Labour Dynamics in Australia (HILDA) Survey	x	x	✓	✓	✓	✓	No information on risk factors or presence of condition.
North West Adelaide Health Study (NWAHS)	x	x	✓	✓	x	✓	No information on risk factors or presence of condition.
Concord Health and Ageing in Men Project (CHAMP)							Out of scope – pre-2015.
Ten to Men Study	x	x	?	✓	x	✓	No information on risk factors or presence of condition.
Raine Study	x	x	x	✓	✓	✓	No information on risk factors or presence of condition.
Australian Longitudinal Studies of Ageing	✓	x	✓	✓	?	✓	Last wave conducted in 2014
Florey Adelaide Male Ageing Study							Out of scope – pre-2015.
Linked data sources							
DOMINO	x	x	x	✓	✓	✓	Includes the DSP. No information on risk factors or presence of condition.

(continued)

Type and name of data set	Some level of information available in priority information area						Comments
	Risk factors	Presence of condition	Treatment and management	Individual impact	Population impact	Demographics of the study sample	
Other data sources							
Australian Burden of Disease Study 2022 (ABDS)	✓	✗	✗	✗	✓	✓	Collection is about disease burden.
IQVIA pharmacy retail data	✗	✗	✓	✓	✗	✓	No information on risk factors or presence of condition.
MyHealth Record							Potential future data source.
Primary Health Care Data Asset							In early stages of development, potential future data source.
Census 2021	✗	✗	✗	✓	✓	✓	No information on lymphoedema or associated risk factors available

Appendix C: Data source appraisals

Administrative data sources

Australian Prudential Regulation Authority (APRA) – private health insurance data	
Type of data source	Administrative (national).
Brief description	<p>The Australian Prudential Regulation Authority (APRA) is an independent statutory authority that supervises institutions across banking, insurance and superannuation, and is accountable to the Australian Parliament.</p> <p>APRA operates under laws determined by the Australian Parliament. These laws grant APRA formal powers to establish prudential standards, and other components of the prudential framework, that are aimed at maintaining the safety and soundness of the institutions that APRA regulates.</p> <p>Among other insurers, APRA oversees private health insurers. There are 37 private health insurance agencies registered with APRA.</p>
Purpose(s)	The statistics provide industry aggregate summaries of key financial and membership statistics. Specific sets of statistics are also provided in the areas of membership, coverage, benefits paid, medical gap, prostheses, and medical services (MBS services).
Collection methodology	Compiled primarily from regulatory returns submitted to APRA under the Financial Sector (Collection of Data) Act 2001 by authorised Private Health Insurance companies.
Scope and coverage	Persons with private health insurance (private hospital cover).
Geographic coverage	National.
Frequency/timing	Quarterly.
Basic collection count	Number of insured services.
Size	At 31 March 2022 14,186,527 people (55% of the population) had some form of general treatment cover and 11,621,039 people (45% of the population) were covered by hospital treatment cover.
Collection management organisation	Australian Prudential Regulation Authority.
Further information	https://www.apra.gov.au/quarterly-private-health-insurance-statistics

Australian Prudential Regulation Authority (APRA) – Private Health Insurance data (continued)

Priority information areas	Risk factors	✓	A number of procedures involving the dissection or excision of lymph nodes are risk factors for the development of secondary lymphoedema.
	Presence of condition	✗	No data.
	Treatment and management	✓	<p>45585 - Liposuction (suction assisted lipolysis) to one regional area (one limb or trunk), other than a service associated with a service to which item 31525 applies, if:</p> <p>(a) the liposuction is for:</p> <p style="padding-left: 40px;">(i) the treatment of Barraquer-Simons syndrome, lymphoedema or macrodystrophia lipomatosa; or</p> <p style="padding-left: 40px;">(ii) the reduction of a buffalo hump that is secondary to an endocrine disorder or pharmacological treatment of a medical condition; and</p> <p>(b) photographic and/or diagnostic imaging evidence demonstrating the clinical need for this service is documented in the patient notes (Anaes.)</p> <p>45048 – lymphoedematous tissue or lymphangiectasis, of lower leg and foot, or thigh, or upper arm, or forearm and hand, major excision of (Anaes.) (Assist.)</p> <p>Data for prosthetic benefits paid is available, however the detail provided is not granular enough to identify compression garments.</p>
	Individual impact	✓	Episodes, days – hospital treatment, days – hospital substitute treatment.
	Population impact	✓	Benefits paid Chronic Disease Management Program, benefits paid general treatment, Benefits paid hospital benefits, medical benefits, prostheses benefits, gross benefit, fees excluding Medicare benefit, fees charged, benefits, total benefits, excess/ co-payments, amount charged, Medicare benefit, Fund benefit, Gap.
	Demographics of the study sample	✓	Age, gender, state/ territory, dependent child, single equivalent unit(s), nursing home type patients.

Department of Veterans' Affairs (DVA) client data	
Type of data source	Administrative (national).
Brief description	<p>Veterans of the Australian Defence Force are an important group of people for health and welfare monitoring. The unique nature of military service means some veterans can experience health and welfare challenges above those of the Australian population.</p> <p>DVA has data pertaining to government programs for serving and former serving members of the ADF, Australian Federal Police and their families.</p> <p>DVA clients are people who receive support from DVA and may be serving or ex-serving members of the ADF, or the family, partner or dependant of a serving or ex-serving ADF member. Current or ex-serving ADF personnel and their families may be eligible for a range of benefits, including ongoing or one-time payments, to support them in certain situations. DVA card holders are eligible veterans, their widow(er)s and/or dependants who have been issued with a Gold or White health card.</p> <p>DVA data has information on Pensioner's summary statistics, Treatment population statistics, Top-20 accepted conditions (recent conflicts & Vietnam), Population projections, Local Government Area (LGA) profiles, Federal Electoral profiles.</p> <p>The treatment population consists of veterans and dependants entitled to treatment at departmental expense and who have been issued a DVA Gold or White card under the:</p> <ul style="list-style-type: none"> • Veterans' Entitlements Act 1986 (VEA) • Military Rehabilitation and Compensation Act 2004 (MRCA) • Safety, Rehabilitation and Compensation (Defence-related Claims) Act 1988 (DRCA) • Australian Participants in British Nuclear Tests and British Commonwealth Occupation Force (Treatment) Act 2006, and • Treatment Benefits (Special Access) Act 2019
Purpose(s)	The purpose of this data set is to collect information on the financial wellbeing, physical wellbeing, self-sufficiency and quality of life of eligible veterans and their dependants through access to income support, compensation, health and other care services that promote early intervention, prevention and treatment and other support services, including advice and information about entitlements.
Collection methodology	Administrative data on veterans on pensions and claiming treatment.
Scope (theoretical coverage of relevant population) and coverage (actual)	Veterans and their families registered with DVA.
Geographic coverage	All states and territories, Australia.
Frequency/timing	Ongoing. Quarterly (Pension summary, treatment population, LGA, federal electoral profiles). Half-yearly (top-20 accepted conditions, executive summary, summary reports at a glance).
Basic collection count	Number of pensions, treatment population (veterans and dependants who have the treatment entitlement cards), number of veterans with accepted conditions.

Department of Veterans' Affairs (DVA) client data (continued)			
Size	As of March 2022: <ul style="list-style-type: none"> total DVA clients: 338,004 treatment population: 272,959 net total persons receiving income support or a compensation pension from the DVA: 172,253 veterans with an accepted condition: 22,236 total number of accepted conditions: 85,509 		
Collection management organisation	The Department of Veterans' Affairs (DVA).		
Further information	Statistics about the veteran population Department of Veterans' Affairs (dva.gov.au)		
Priority information areas	Risk factors	✓	Information on risk factors associated with the development of secondary lymphoedema are available.
	Presence of condition	✓	Lymphoedema is available.
	Treatment and management	✓	PH41 Lymphoedema treatment*. OT26 Lymphoedema treatment*. PH92 Consumables clinically required immediately during the consultation/ treatment. PH93 Consumables clinically required for treatment after consultation. OT71 Consumables clinically required immediately during the consultation/ treatment. OT72 Consumables clinically required for treatment after consultation. PH94 Small medical aids and appliances. OT75 Small medical aids and appliances. *Note: Items PH41 and OT26 should be claimed for all aspects of clinical treatment.
	Individual impact	?	Unknown.
	Population impact	✓	Expenditure on services provided to veterans and costs of services.
	Demographics of the study sample	✓	Age, sex, usual residence (local government area) of veteran/ dependant.

Medicare Benefits Schedule (MBS)	
Type of data source	Administrative (national).
Brief description	<p>The Medicare Benefits Schedule (MBS) data collection contains information on services that qualify for a benefit under the Health Insurance Act 1973 and for which a claim has been processed. The database comprises information about MBS claims (including benefits paid), patients and service providers.</p> <p>The MBS is a list of all health services that the Government subsidises. A team of medical experts keeps the list up to date, safe and best practice.</p> <p>MBS data excludes:</p> <ul style="list-style-type: none"> • services that have been provided in public hospitals to public patients • services provided in outpatient or emergency departments of public hospitals. <p>These are covered in separate hospitals data.</p>
Purpose(s)	The purpose of Medicare is to provide people with subsidised medical services. Medicare data provides broad information on the type of services used and the benefit paid by Medicare for the service.
Collection methodology	Providers or patients submit claims for payment reflecting Medicare activity.
Scope and coverage	Medicare is available to Australian and New Zealand citizens, permanent residents in Australia, and people from countries with reciprocal agreements. Information will be missing if individuals or doctors fail to lodge claim information. This should be a rare occurrence, as there is a financial incentive to do so.
Geographic coverage	All states and territories, Australia.
Frequency/timing	Ongoing.
Basic collection count	Number of subsidised medical/ allied health services.
Size	In 2020–21, the total number of all services was 465,870,553.
Collection management organisation	Medicare is managed by the Department of Health and Aged Care and administered by Services Australia.
Further information	http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Home

Medicare Benefits Schedule (MBS) (continued)

Priority information areas	Risk factors	✓	A number of procedures involving the dissection or excision of lymph nodes are risk factors for the development of secondary lymphoedema.
	Presence of condition	✗	No data.
	Treatment and management	✓	45585 - Liposuction (suction assisted lipolysis) to one regional area (one limb or trunk), other than a service associated with a service to which item 31525 applies, if: (a) the liposuction is for: (i) the treatment of Barraquer-Simons syndrome, lymphoedema or macrodystrophia lipomatosa; or (ii) the reduction of a buffalo hump that is secondary to an endocrine disorder or pharmacological treatment of a medical condition; and (b) photographic and/or diagnostic imaging evidence demonstrating the clinical need for this service is documented in the patient notes (Anaes.) 45048 – lymphoedematous tissue or lymphangiectasis, of lower leg and foot, or thigh, or upper arm, or forearm and hand, major excision of (Anaes.) (Assist.)
	Individual impact	✗	No data.
	Population impact	✓	Expenditure by Medicare on services provided by GPs, private hospitals and some allied health professionals and cost of services.
	Demographics of the study sample	✓	Sex, age, usual residence of patient (various levels such as SLA, RRMA). Indigenous status.

National Aged Care Data Clearing House	
Type of data source	Administrative (national)
Brief description	The National Aged Care Data Clearing House (NACDC) is an independent national data collection set which explores a broad range of Australian aged care data. The NACDC contains 70+ data tables exploring residential, community based and flexible aged care programs since 2013.
Purpose(s)	The primary purpose of the NACDC is to capture aged care service levels, system capacity and overall assessment of individuals receiving care. Through capturing data across multiple geographic locations, it enables stakeholders to extrapolate trends and patterns.
Collection methodology	<p>The NACDC obtains information from the following administrative sources:</p> <ul style="list-style-type: none"> • Department of Human Services • Department of Social Services • Department of Health and Aged Care • Aged Care Quality and Safety Commission • Aged Care Financing Authority <p>Further data is also collated through analysing:</p> <ul style="list-style-type: none"> • population projections • linked data • aged care workforce survey and census data • quality Indicators for residential aged care • consumer experience levels in residential aged care. The collection comprises 10 items regarding the experience of care, to which the client (or a representative, if required) responds on a 4 or 5-point scale.
Scope (theoretical coverage of relevant population) and coverage (actual)	<p>The NACDC is an independent database that is responsible for the storage of all government funded aged care activity data. The database aims to assess 4 main aspects of the Australian aged care system including:</p> <ul style="list-style-type: none"> • assessments of current and prior care • services providing care • providers operating services • system capacity within facilities.
Geographic coverage	All states and territories, Australia. New South Wales excluded in 2015.
Frequency/timing	Annual reporting on the operation of the Aged Care Act 1997. Current years 1 July 1997 to 30 June 2021.

National Aged Care Data Clearing House (continued)		
Basic collection count		<ul style="list-style-type: none"> • people using aged care • places • assessments • services • providers. <p>Aged care admissions refer to the number of entries into an aged care service over a specified period, rather than the number of people who entered the service. People are counted as an 'admission' to aged care when they start using a service and are counted again if they return (excluding short periods of leave).</p> <p>A person's first admission to an aged care service is counted only once, although they will have multiple first admissions should they use a range of aged care services (e.g. one first admission to home care, and one first admission to transition care).</p>
Size		<p>In 2020–21, total admissions to aged care services in Australia were:</p> <ul style="list-style-type: none"> • 250,000 admissions (over 67,000 to permanent residential care, over 82,000 to respite residential care, over 77,000 to home care, and over 23,000 to transition care). • Number of first admissions were: 58,197 to permanent residential care; 50,084 to respite residential care and 68,385 to home care. Data are not available for transition care first admissions. • There are 5,755 operational aged care services available, 229,547 operational aged care places, 219,105 approved residential aged care providers, 187,393 total number of completed aged care assessments of all people.
Collection management organisation		Australian Institute of Health and Welfare.
Further information		https://www.aihw.gov.au/about-our-data/our-data-collections/national-aged-care-data-clearinghouse
Priority information areas	Risk factors	<p>✓</p> <p>Medical conditions</p> <p>0201 Head & neck cancer 0205 Skin cancer 0206 Breast cancer 0207 Prostate cancer 1201 Skin and subcutaneous tissue infections (includes impetigo, boil, cellulitis). 1301 Rheumatoid arthritis</p> <p>Complex health care</p> <p>5 Complex skin integrity management for residents with compromised skin integrity who are usually confined to bed and/ or chair and cannot self-ambulate. 9 Management of chronic infectious conditions</p> <ul style="list-style-type: none"> • Tuberculosis <p>10 Management of chronic wounds, including varicose and pressure ulcers, and diabetic foot ulcers.</p>
	Presence of condition	<p>✓</p> <p>Medical conditions</p> <p>1729 Oedema n.e.c</p> <p>Body function impairment</p> <p>5006 Immunological system functions (includes functions of cell-mediated immunity, functions of lymph nodes and lymphatic vessels, hypersensitivity reactions, allergic reactions, lymphoedema).</p>

National Aged Care Data Clearing House (continued)		
Treatment and management	✓	Complex health care 12b Management of: <ul style="list-style-type: none"> • 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.
Individual impact	✓	Activity limitations, type of current assistance, source of current assistance, whether receiving government support program, recommended assistance, recommended government program, behavioural assessments, medication needs, routine care, functional status.
Population impact	✓	Income amount, source and frequency; assistance amount, minutes and quantity, fees charged.
Demographics of the study sample	✓	Sex, age, suburb, postcode, state, local government area, resident status, Indigenous status, language spoken, country of birth, living arrangements usual residence, statistical area, pension benefit status, DVA card status, marital status.

National Disability Insurance Scheme (NDIS)	
Type of data source	Administrative (national).
Brief description	<p>The National Disability Insurance Scheme (NDIS) provides funding to eligible people with disabilities based on their individual needs. Every NDIS participant has an individual plan that lists their goals and the funding they have received. NDIS participants use their funding to purchase supports and services that will help them achieve their goals.</p> <p>Supports funded by the NDIS include daily personal activities, transport to facilitate participation, workplace help, therapeutic supports, help with household tasks, help with aids or equipment assessment, home modification, mobility equipment and vehicle modifications.</p> <p>The National Disability Insurance Agency (NDIA) is responsible for delivering the NDIS.</p>
Purpose(s)	The National Disability Insurance Scheme (NDIS) supports people with a permanent and significant disability that affects their ability to take part in daily activities.
Collection methodology	<p>The information collected by the NDIA includes (but is not limited to) personal information about participants and other users of services, and about employees, contractors and providers.</p> <p>Information is often collected from people directly or from people who are authorised to represent them. Information is sometimes collected from a third party if an individual has consented, been informed of this practice, or would reasonably expect the NDIA to collect information in this way. An example of this is collecting information from a health care service, such as a residential aged care facility, which is managing a participants care. The NDIA or contracted service providers may also collect information from third party disability support providers, state and territory governments and other Australian Government entities where this collection is authorised under law.</p> <p>For more information see Privacy NDIS</p>
Scope and coverage	<p>To access the NDIS, the following requirements must be met:</p> <ul style="list-style-type: none"> • have a permanent and significant disability that affects the ability to take part in everyday activities • be aged less than 65 when the scheme is first accessed • be an Australian citizen, a permanent resident or a New Zealand citizen who holds a Protected Special Category Visa • live in an area where the NDIS is available. <p>A person meets the disability requirements (National Disability Insurance Scheme Act 2013) if:</p> <p>(a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and</p> <p>(b) the impairment or impairments are, or are likely to be, permanent; and</p> <p>(c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:</p> <ul style="list-style-type: none"> (i) communication (ii) social interaction (iii) learning (iv) mobility (v) self-care (vi) self-management, and; <p>(d) the impairment or impairments affect the person's capacity for social and economic participation, and;</p>

			(e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime. To be eligible for the NDIS, the following characteristics are assessed: <ul style="list-style-type: none"> • whether support from a person is needed because of a permanent and significant disability • whether special equipment is used because of a permanent and significant disability • whether supports are needed now to reduce future needs.
Geographic coverage			Available across all states and territories (Western Australia was fully rolled out by 2020).
Frequency/timing			Quarterly. Extra info: The NDIS began on 1 July 2013. The trial period finished in July 2016.
Basic collection count			There is one row per quarter for every customer who is an active participant in the NDIS.
Size			On 31 March 2022, the NDIS had 518,668 participants.
Collection management organisation			National Disability Insurance Agency (NDIA)
Further information			https://www.ndis.gov.au/
Priority information areas	Risk factors	✘	Limited. Cancers grouped under metastatic cancer, rheumatoid arthritis.
	Presence of condition	✓	Lymphoedema is available. The NDIA receives information from participants on diagnoses, noting no independent validation of the diagnosis is undertaken. These diagnoses have been grouped into disability groups on a one-to-one basis, recognising that there is not always a perfect one-to-one match. A primary disability is chosen based on the disability with the greatest impact on functional capacity, noting that there are limitations with this approach.
	Treatment and management	✓	Supports committed (e.g. supported independent living), supports received, participant pathway data.
	Individual impact	✓	Participant outcomes data, participant satisfaction data.
	Population impact	✓	Supports paid.
	Demographics of the study sample	✓	Age, gender, culturally and linguistically diverse (CALD) status, residential information (to SA4 level).

National Hospital Morbidity Database (NHMD)	
Type of data source	Administrative (national).
Brief description	The NHMD is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian hospitals.
Purpose(s)	To provide information on admitted patient care, such as demographic, administrative and length of stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning.
Collection methodology	The data supplied are based on the National Minimum Data Set for admitted patient care. Data are supplied to the AIHW by state and territory health authorities under the terms of the National Health Information Agreement.
Scope and coverage	The NHMD is a comprehensive data set that has records for episodes of admitted patient care from essentially all public and private hospitals in Australia. In 2020–21, there were 697 public hospitals in Australia, while the most recent data for private hospitals (for 2016–17) show that there were 657 private hospitals (including day hospital facilities).
Geographic coverage	All states and territories, Australia.
Frequency/timing	Annually since 1993–94.
Basic collection count	Number of separations (or hospitalisations). A separation is an episode of care for an admitted patient, which can be a total hospital stay (from admission to discharge, transfer or death), or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation).
Size	There were 11.8 million separations, 7 million in public hospitals and 5 million in private hospitals recorded in the NHMD in 2020–21.
Collection management organisation	The NHMD is compiled by the AIHW from data supplied by the state and territory health authorities under the terms of the National Health Information Agreement.
Further information	https://meteor.aihw.gov.au/content/index.phtml/itemId/724188

National Hospital Morbidity Database (NHMD) (continued)			
Priority information areas	Risk factors	✓	Known risk factors for the development of secondary lymphoedema are available (e.g. breast cancer, excision procedures on lymphatic structure, venous diseases, cellulitis).
	Presence of condition	✓	Not suitable for whole-of-population prevalence: it includes only those where the condition contributed to the hospitalisation, and it is 'event' based (it is not possible to identify multiple admissions for an individual without undertaking linkage). I890 – Lymphoedema not elsewhere classified I97.2 – Postmastectomy lymphoedema syndrome I97.83 – Postprocedural lymphocele, lymphoedema and chylothorax Q82.0 – Hereditary lymphoedema
	Treatment and management	✓	90283-00 – Other procedures on lymphatic structures 1667 – Excision of lymphoedematous tissue 45048-00 – Excision of lymphoedematous tissue of arm 45048-01 – Excision of lymphoedematous tissue of forearm and hand 45048-02 – Excision of lymphoedematous tissue of thigh 45048-03 – Excision of lymphoedematous tissue of leg and foot 45048-04 – Excision of lymphoedematous tissue of other site
	Individual impact	✓	Length of stay for separations is available.
	Population impact	×	No data.
	Demographics of the study sample	✓	Sex, age, Indigenous status, area of usual residence (SA2 level).

National Mortality Database (NMD)	
Type of data source	Administrative (national).
Brief description	The NMD contains information pertaining to deaths registered in Australia since 1964. Information is provided on the underlying cause of death (the disease or condition leading directly to death). From 1997, data are available on the associated causes of death (diseases or conditions other than the underlying cause that contributed to the death).
Purpose(s)	The NMD is used by the AIHW to produce population-level analyses for: monitoring and surveillance of mortality due to specific chronic diseases (or all causes combined); burden of disease research; and to inform Closing the Gap and other Council of Australian Governments (COAG) indicators. It is also used to fulfil data requests for external researchers.
Collection methodology	Deaths are registered by the registrars of Births, Deaths and Marriages in each state and territory. Death registration is compulsory. The cause of death is certified by the medical practitioner or the coroner and coded using the International Statistical Classification of Diseases and Related Health Problems (ICD). Demographic and administrative information about the deceased is collected on the Death Information Form, filled out by the deceased's next of kin in conjunction with the funeral director.
Scope and coverage	<p>The Australian Bureau of Statistics (ABS) Death Registrations collection includes all deaths that occurred and were registered in Australia, including deaths of persons whose place of usual residence was overseas. Deaths of Australian residents that occurred outside Australia may be registered by individual registrars but are not included in ABS death statistics.</p> <p>All deaths in Australia need to be registered, but there can be delays in the registration of deaths due to: lags in coronial processes; delays at the state and territory level; and data processing or data transfer lags between the state and territory registries and the ABS. This can result in some deaths occurring in a particular year not being registered until the following year or later.</p>
Geographic coverage	All states and territories, Australia.
Frequency/timing	The ABS issues summaries of cause of death annually and the AIHW updates the NMD once these data become available.
Basic collection count	Number of deaths.
Size	There were 161,300 deaths registered in Australia in 2020 (84,588 males; 76,712 females).
Collection management organisation	The information is provided to the ABS for coding the cause of death and compiling into national aggregate statistics. The AIHW manages the NMD.
Further information	Causes of Death, Australia, 2020 Australian Bureau of Statistics (abs.gov.au)

National Mortality Database (NMD) (continued)			
Priority information areas	Risk factors	✓	Known risk factors for the development of secondary lymphoedema are available (e.g. the main types of cancers, venous diseases, cellulitis).
	Presence of condition	✓	I89.0 – Lymphoedema not elsewhere classified I97.2 – Postmastectomy lymphoedema syndrome Q82.0 – Hereditary lymphoedema
	Treatment and management	✗	No data.
	Individual impact	✓	Death.
	Population impact	✗	No data.
	Demographics of the study sample	✓	Sex, age at death, remoteness of usual residence, Indigenous status, country of birth.

National Non-Admitted Patient (episode-level) Database (NNAP(e)D)	
Type of data source	Administrative (national).
Brief description	<p>Non-admitted patients are patients who do not undergo a hospital's formal admission process and do not occupy a hospital bed. Instead, they receive services as an outpatient. The types of care they receive include consultations with specialist medical practitioners, the provision of diagnostic or other procedures, and allied health or clinical nurse specialist services.</p> <p>The NNAP(e)D holds episode-level data on non-admitted patients service events in public hospital outpatient clinics. This includes selected patient characteristics; the type of outpatient clinic; whether the episode was an individual or a group service event; the source of the request for service; the service delivery setting; the service delivery mode and the principal source of funding.</p>
Purpose(s)	<p>The aim of the Non-admitted Patient Care data collections is to report episode-level data on non-admitted activity in Australia's public hospital system. Data suppliers report non-admitted patient activity in either aggregate or episode-level format.</p> <p>The episode level data is collected under the Non-admitted patient National Best Endeavours Data Set (NAP NBEDS) while the aggregate level data is collected under the Non-admitted patient care aggregate National Best Endeavours Data Set (NAPC aggregate NBEDS).</p>
Collection methodology	<p>Interaction with the Non-admitted patient (NAP) National Best Endeavours Data Set (NBEDS) and Non-admitted patient care (NAPC) aggregate NBEDS 2019–20.</p> <p>The NAP NBEDS and NAPC aggregate NBEDS work together to collect data on non-admitted activity in the public hospital system. The principle should be applied that no service event is to be double-counted or included in both the NAP NBEDS or the NAPC aggregate NBEDS. Therefore, activity that is reported through the NAP NBEDS should not be reported through the NAPC aggregate NBEDS.</p> <p>It is intended that activity should be reported primarily at the patient level through the NAP NBEDS, and where activity is not able to be reported at a patient level through the NAP NBEDS, this activity should be reported through the NAPC aggregate NBEDS. If the following data elements in the NAP NBEDS cannot be reported as a minimum for a specific service event, then the service event should be reported through the NAPC aggregate NBEDS.</p> <p>Each year the collection increasingly reports on episode-level data, however not all data suppliers are able to report data in this format. In 2020–21, 75% of data provided to the non-admitted patient care data collections was episode-level data, and the aim is for the collection to eventually report only on episode-level data.</p>

National Non-Admitted Patient (episode-level) Database (NNAP(e)D) (continued)

Scope and coverage	<p>For 2020–21, the scope of the NAP NBEDS is non-admitted patient service events provided by:</p> <ul style="list-style-type: none"> • public hospitals • Local Hospital Networks (LHNs) • other public hospital services that are managed by a state or territory health authority and are included in the General list of in-scope public hospital services, developed under the National Health Reform Agreement (2011). <p>It holds episode-level data including:</p> <ul style="list-style-type: none"> • selected patient characteristics • the type of outpatient clinic • whether the episode was an individual or a group service event • the source of the request for service • the service delivery setting • the service delivery mode • the type of care provided • whether the service involved care from multiple health care providers • the funding source for the service event. <p>For the NNAP(e)D, a record is included for each service event, not for each patient, so patients who receive more than one non-admitted patient service event in the year have more than one record in the NNAP(e)D.</p>
Geographic coverage	Australia (excluding South Australia in 2020–21).
Frequency/timing	Annual. Due to changes in coverage over the period 2014–15 to 2020–21 changes in the numbers of service events reported between 2014–15 and 2020–21 should be treated with caution.
Basic collection count	Non-admitted patient service events. For the NNAP(e)D, counts represent each service event, not each patient. Therefore, patients who receive more than one non-admitted patient service event in the reporting period will have more than one record in the NNAP(e)D.
Size	<p>In 2020–21:</p> <ul style="list-style-type: none"> • 46.8 million non-admitted patient care service events were provided in public hospitals. • 35.1 million episode-level service events were reported.
Collection management organisation	AIHW
Further information	<p>Non-admitted-patient-care-2020-21-Appendixes.pdf.aspx (aihw.gov.au) https://meteor.aihw.gov.au/content/699590</p>

**National Non-Admitted Patient (episode-level) Database (NNAP(e)D)
(continued)**

Priority information areas	Risk factors	✓	40.13 Wound management 40.31 Burns 20.48 Multidisciplinary burns clinic
	Presence of condition	✗	Lymphoedema not available.
	Treatment and management	✗	40.03 Aids and appliances
	Individual impact	✗	No data.
	Population impact	✗	No data.
	Demographics of the study sample	✓	Age group, sex, Indigenous status, remoteness, socioeconomic status, birth country.

Linked data sources

Multi-Agency Data Integration Project (MADIP)	
Type of data source	Linked census, administrative and survey data.
Brief description	MADIP is a secure data asset combining information on health, education, government payments, income and taxation, employment, and population demographics (including the Census) over time.
Purpose(s)	<p>MADIP provides whole-of-life insights about various population groups in Australia, such as the interactions between their characteristics, use of services like health care and education, and outcomes like improved health and employment. MADIP was first established in 2015 in response to a review of the Australian Government arrangements for data integration that found more focus was needed to access the substantial value inherent in public data. The MADIP data asset was further developed between 2017 and 2020 through the Data Integration Partnership for Australia (DIPA). The project is enabled through a partnership of agencies, which includes:</p> <ul style="list-style-type: none"> • Australian Bureau of Statistics • Australian Taxation Office • Department of Education, Skills and Employment • Department of Health and Aged Care • Department of Social Services • Services Australia.
Collection methodology	<p>The ABS is trusted as the accredited Integrating Authority for MADIP. The ABS collects and combines the data, provides access to authorised researchers, and protects privacy and keeps information secure at all times. The Person Linkage Spine allows the ABS to link data sets through a spine of key information, separate from the main body of data. This approach improves privacy and security and enables more efficient and higher quality linkage. The Spine supports the regular maintenance and expansion of MADIP. The data sets included in MADIP are:</p> <ul style="list-style-type: none"> • Australian Census Longitudinal Data set • Census of Housing and Population • Causes of Death • National Health Survey (2014–15 and 2017–18) • Survey of Disability, Ageing and Carers 2018 • Personal Income Tax Return • Personal Income Tax Payment Summary • Australian Apprenticeships Incentives Programme • Australian Early Development Census • Higher Education Information Management System (Previously HIED) • Medicare Consumer Directory (previously MEDB) • Medicare Provider Directory • Medicare Benefits Schedule • Pharmaceutical Benefits Scheme • DSS Data Exchange • Data Over Multiple Individual Occurrences (DOMINO)

	<ul style="list-style-type: none"> • Skilled Migration Points Data • Net Overseas Migration – Travellers • Visa data from the Travel and Migration Processing System (TRIPS) and Settlements Database (SDB) • Person information derived from MADIP spine • Total VET Activity.
Scope (theoretical coverage of relevant population) and coverage (actual)	<p>The Basic Longitudinal Extract (2011–2016 Cohorts) contains data for the resident Australian population between 1 January 2011 and 31 December 2016 over the 2011–2016 reference period. The scope of the microdata product is defined as all persons in the Person Linkage Spine who met one or more of the following conditions:</p> <ul style="list-style-type: none"> • they accessed at least one MBS service at any time between 2011 and 2016 • they obtained at least one PBS prescription at any time between 2011 and 2016 • they were a benefit payment recipient according to the SSRI at any time between 2011 and 2016 • they submitted a personal income tax (PIT) return for at least one financial year between 2010–11 and 2015–16 • they were in an approved training contract with an employer according to the AT data at any time between 2011 and 2016, or • they were enumerated in the 2016 Census. <p>The Person Linkage Spine is comprised of all persons who were captured in the MEDB, SSRI or PIT data sets at any point between 2006 and 2016. Any persons who were captured in the MEDB but had no activity recorded in any of the other source data sets are excluded from the microdata product.</p>
Geographic coverage	National, state, regional.
Frequency/timing	The MADIP data asset was first developed in 2015 with further development between 2017 and 2020 through the Data Integration Partnership for Australia (DIPA).
Basic collection count	Person-level data.
Size	Spine contains 35.99 million elements in June 2020
Collection management organisation	ABS.
Further information	Multi-Agency Data Integration Project (MADIP) Australian Bureau of Statistics (abs.gov.au)

Multi-Agency Data Integration Project (MADIP) (continued)

Priority information areas	Risk factors	✓	<p>MBS</p> <p>A number of procedures involving the dissection or excision of lymph nodes are risk factors for the development of secondary lymphoedema.</p> <p>NHS</p> <p>Cancer-related risk factors:</p> <p>110106. Skin Cancer</p> <p>110107. Breast Cancer</p> <p>110108. Cancer of female genital organs</p> <p>110109. Cancer of male genital organs</p> <p>Non-cancer related risk factors:</p> <p>180702. Varicose veins</p> <p>210201. Dermatitis and eczema</p> <p>210301. Psoriasis</p> <p>220101. Rheumatoid arthritis</p> <p>281101. Burns</p> <p>SDAC</p> <p>203. Skin cancer</p> <p>204. Breast cancer</p> <p>205. Prostate cancer</p> <p>Non-cancer-related</p> <p>101. Tuberculosis</p> <p>1201. Skin and subcutaneous tissue infections</p> <p>1202. Skin allergies (eczema and dermatitis)</p> <p>1204. Scars</p>
	Presence of condition	✓	<p>Causes of death</p> <p>I890 – Lymphoedema not elsewhere classified</p> <p>I97.2 – Postmastectomy lymphoedema syndrome</p> <p>Q82.0 – Hereditary lymphoedema</p>
	Treatment and management	✓	<p>MBS</p> <p>45585 – Liposuction (suction assisted lipolysis) to one regional area (one limb or trunk), other than a service associated with a service to which item 31525 applies, if:</p> <p>(a) the liposuction is for:</p> <p style="padding-left: 40px;">(i) the treatment of Barraquer-Simons syndrome, lymphoedema or macrodystrophia lipomatosa; or</p> <p style="padding-left: 40px;">(ii) the reduction of a buffalo hump that is secondary to an endocrine disorder or pharmacological treatment of a medical condition; and</p> <p>(b) photographic and/or diagnostic imaging evidence demonstrating the clinical need for this service is documented in the patient notes (Anaes.)</p> <p>45048 – lymphoedematous tissue or lymphangiectasis, of lower leg and foot, or thigh, or upper arm, or forearm and hand, major excision of (Anaes.) (Assist.)</p>

Multi-Agency Data Integration Project (MADIP) (continued)

	Individual impact	✓	<p>CENSUS Employment type.</p> <p>NHS Disability status; schooling and employment restriction.</p> <p>SDAC Data items include disability status, core-activity restrictions (self-care, mobility and communication), schooling and employment limitations, housing, transport, difficulty and need for assistance with specific activities, difficulty and need for assistance with broad activities, ability to participate in cultural, sport, social and/or community activities, discrimination, feelings of safety, patient experience, self-assessed health and mental wellbeing.</p>
	Population impact	✓	<p>ATO Taxable income.</p> <p>DOMINO Benefits.</p> <p>MBS Expenditure by Medicare on services provided by GPs, private hospitals and some allied health professionals and cost of services.</p> <p>SDAC Impact of the caring role on carers and their self-assessed health and mental wellbeing, the effect of the caring role on carers' financial situation.</p>
	Demographics of the study sample	✓	<p>Age as at request date; Country of birth; Date of death; Day of death, Ever reported as Torres Strait Islander, Ever reported as Aboriginal, Ever reported as Indigenous; Gender; Month of birth; Month of death; Year of birth; Year of death; Indigenous Area; Index of Education and Occupation – deciles at national level; Index of Education and Occupation – deciles at state level; Index of Economic Resources – deciles at national level; Index of Economic Resources – deciles at state level; Indigenous Location; Index of Relative Socio-economic Advantage and Disadvantage – deciles at national level; Index of Relative Socio-economic Advantage and Disadvantage – deciles at state level; Index of Relative Socio-economic Disadvantage – deciles at national level; Index of Relative Socio-economic Disadvantage – deciles at state level; Remoteness Area; Reference period as required (monthly, quarterly, yearly); SA1 of residence on the first day of the reference period; State of residence on the first day of the reference period.</p>

National Integrated Health Services Information Analysis Asset (NIHSI AA)	
Type of data source	Administrative (national).
Brief description	<p>The NIHSI is a major national linked health data asset for health research and analysis. The NIHSI comprises a selection of data items from each of the following AIHW collections:</p> <ul style="list-style-type: none"> • Hospitals data held in the National Hospital Data Collection • National Hospital Morbidity Database • National Non-Admitted Patient Emergency Department Care Database • National Non-Admitted Patient Databases, Aggregate and unit record • National Death Index • National Aged Care Data Clearinghouse • Medicare Benefits Schedule, and • Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme.
Purpose(s)	<p>NIHSI's functions include:</p> <ul style="list-style-type: none"> • identifying patterns of use and effectiveness of health and residential aged care • recognising health risks for diverse cohorts • monitor accessibility and effectiveness of health services • observing chronic disease management • validation of current treatment pathways • quality and safety control of health services • implementing policies and programs designed to minimise incidence and severity of disease and injury.
Collection methodology	<p>Annual collection of patient health care records from the below administrative linked data sets:</p> <ul style="list-style-type: none"> • Admitted Patient Care • Emergency Department Care • Residential aged care • Medicare Benefits Schedule • Pharmaceutical Benefits Scheme • National deaths and mortality register.
Scope (theoretical coverage of relevant population) and coverage (actual)	<p>NIHSI contains data on admitted patient care services in public hospitals and some private hospitals, emergency department services, and in outpatient services in public hospitals within New South Wales, Victoria (excluding Albury-Wodonga), South Australia, Tasmania, Queensland and the Australian Capital Territory. It also includes Medicare Benefits Schedule (MBS) data; Pharmaceutical Benefits Scheme (PBS) data; Residential Aged Care (RAC) services data and National deaths and mortality data.</p>
Geographic coverage	New South Wales, Victoria (excluding Albury-Wodonga), South Australia, Tasmania, Queensland and the Australian Capital Territory.
Frequency/timing	Annually since 2010–2011.
Basic collection count	Accessing MBS services, PBS prescriptions and number of patients/ visits between health care services.

Priority information areas	Risk factors	✓	Known risk factors for the development of secondary lymphoedema are available (e.g. breast cancer, excision procedures on lymphatic structure, venous diseases, cellulitis).
	Presence of condition	✓	I89.0 – Lymphoedema not elsewhere classified I97.2 – Postmastectomy lymphoedema syndrome I97.83 – Postprocedural lymphocele, lymphoedema and chylothorax Q82.0 – Hereditary lymphoedema
	Treatment and management	✓	NHMD: 90283-00 – Other procedures on lymphatic structures 1667 – Excision of lymphoedematous tissue 45048-00 – Excision of lymphoedematous tissue of arm 45048-01 – Excision of lymphoedematous tissue of forearm and hand 45048-02 – Excision of lymphoedematous tissue of thigh 45048-03 – Excision of lymphoedematous tissue of leg and foot 45048-04 – Excision of lymphoedematous tissue of other site MBS: 45585 – Liposuction (suction assisted lipolysis) to one regional area (one limb or trunk), other than a service associated with a service to which item 31525 applies, if: (a) the liposuction is for: (i) the treatment of Barraquer-Simons syndrome, lymphoedema or macrodystrophia lipomatosa; or (ii) the reduction of a buffalo hump that is secondary to an endocrine disorder or pharmacological treatment of a medical condition; and (b) Photographic and/or diagnostic imaging evidence demonstrating the clinical need for this service is documented in the patient notes (Anaes.) 45048 – Lymphoedematous tissue or lymphangiectasis, of lower leg and foot, or thigh, or upper arm, or forearm and hand, major excision of (Anaes.) (Assist.)
	Individual impact	×	No data.
	Population impact	✓	Expenditure by Medicare on services provided by GPs, private hospitals and some allied health professionals and cost of services. PBS benefits and patient contributions.
	Demographics of the study sample	✓	Sex, age, Indigenous status, country of birth, area of usual residence, remoteness of usual residence, age at death, cause of death, usual residence of patients, state or territory of patient episodes and preferred language.

Victorian Integrated Non-Admitted Health (VINAH) minimum data set	
Type of data source	Linked administrative data.
Brief description	The VINAH data collection integrates patient-level data across many government-funded programs which in turn benefits health services, as they are now supported to collect one set of data elements rather than managing multiple collections across many program streams.
Purpose(s)	<p>The Department of Health & Human Services maintains data around the provision of a range of non-admitted services in Victoria to provide equitable funding to public hospitals and support health services in their planning, policy formulation and epidemiological research.</p> <p>VINAH data provides:</p> <ul style="list-style-type: none"> • activity information (number of clients, active clients, new episodes, closed episodes, active episodes delivery setting, delivery mode). • performance indicator information (response times, waiting times, percentage of care plan developed). • demographic information (age, location, country of birth, living arrangements). • client pathway information (length of stay, relationships with other programs, contacts or appointments per episode, multidisciplinary intervention, referral sources and referral destinations).
Collection methodology	<p>The flow of information to VINAH begins at the health service when the patient is referred, and the patient registration information is entered on the health service's patient administration system (PAS).</p> <p>Currently each Victorian public health service selects its own PAS from commercial software suppliers. The health service is responsible for mapping or deriving (where necessary) the fields and codes used in their system to the fields and codes defined for VINAH.</p> <p>A submission is received when an HL7 extract is uploaded to the Secure Data Exchange on the HealthCollect Portal. At this point, an automated validation of data takes place. A health service can update or delete information already held in the VINAH database by generating and submitting a new HL7 message with an 'update' or 'delete' message of the relevant record. This new information overwrites the existing information held in VINAH.</p> <p>The Victorian Integrated Non-Admitted Health (VINAH) data set collection comprises data from the:</p> <ul style="list-style-type: none"> • Family Choice Program (FCP) • Home Enteral Nutrition (HEN) • Hospital Admission Risk Program (HARP) • Hospital Based Palliative Care Consultancy Team (HBPCCT) • Medi-Hotel • Specialist Clinics (OP) • Palliative Care (PC) • Post-Acute Care (PAC) • Residential In-Reach (RIR) • Subacute Ambulatory Care Services (SACS) • Total Parenteral Nutrition (TPN) • Transition Care Program (TCP) • Victorian HIV Service (VHS) • Victorian Respiratory Support Service (VRSS).

Victorian Integrated Non-Admitted Health (VINAH) minimum data set (continued)			
Scope (theoretical coverage of relevant population) and coverage (actual)	Patients living in Victoria using public non-admitted patient health services over the period 2005–06 to 2020–21 (ongoing).		
Geographic coverage	Victoria.		
Frequency/timing	Annual; VINAH v1 2005–06 to VINAH v17 2022–23. Data reckoned monthly.		
Basic collection count	Campus (A physical site owned by a public health service/ hospital), case (opened when an organisation accepts responsibility for a patient, which results in an episode starting), episode (period during which a patient receives services within a defined program and stream), contact (a contact between a patient and health professional that results in a dated entry being made in the patient record).		
Size	Not available.		
Collection management organisation	Victoria State Government Department of Health.		
Further information	Victorian Integrated Non-Admitted Health (VINAH) data set.		
Priority information areas	Risk factors	✓	<p>Episode health conditions</p> <p>Cancer related:</p> <ul style="list-style-type: none"> Neoplasm, malignant, male reproductive system Neoplasm, malignant, male reproductive system, with metastases Neoplasm, malignant, breast Neoplasm, malignant, eye Neoplasm, malignant, female reproductive system Neoplasm, malignant, head and neck Neoplasm, malignant, melanoma Neoplasm, malignant, prostate Neoplasm, malignant, skin <p>Non-cancer-related:</p> <ul style="list-style-type: none"> Burn, full thickness (third degree, fourth degree, complex) < 10% of body surface Burn, full thickness (third degree, fourth degree, complex) >= 10% of body surface Burn, partial or deep partial thickness (sunburn with blisters, second degree) >= 10% of body surface Burn, superficial (erythema, sunburn, first degree) >= 10% of body surface Burn, superficial, partial thickness (erythema, sunburn, first degree, second degree) < 10% of body surface Cellulitis or skin infection Chronic venous insufficiency with skin ulcer Chronic venous insufficiency without skin ulcer <p>Episode other factors affecting health</p> <ul style="list-style-type: none"> Impaired mobility
	Presence of condition	✓	<p>Episode health conditions</p> <ul style="list-style-type: none"> Lymphoedema
	Treatment and management	✓	Contact professional group, contact project stream, contact purpose, episode program/ stream, episode proposed treatment plan completion, referral in outcome, referral in reason, referral in program/ stream, referral in service type, referral out service type.

	Individual impact	✘	No data.
	Population impact	✘	No data.
	Demographics of the study sample	✓	Contact account class, Indigenous status, preferred language, birth country, birth date, residency status, carer availability, date of death, place of death, living arrangement, sex, accommodation type, usual residence locality name and postcode.

Survey-based data sources

Australian Bureau of Statistics (ABS) National Health Survey (NHS)	
Type of data source	Survey (national).
Brief description	The NHS is designed to obtain national information on the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle.
Purpose	<p>The survey was designed to collect a range of information about the health of Australians, including:</p> <ul style="list-style-type: none"> • prevalence of long-term health conditions • health risk factors such as smoking, overweight and obesity, alcohol consumption and physical activity, and • demographic and socioeconomic characteristics.
Collection methodology	<p>The NHS 2020–21 data was collected via a self-completed online form due to the COVID-19 pandemic. There were no face-to-face interviews. Households were randomly selected to participate in the survey. To complete the survey a member of the selected household was required to register and complete the household form.</p> <p>Proxy interviews were accepted for selected adults where the selected adult was present during the interview. This resulted in a large increase in proxy interviews for the 2020–21 NHS; approximately 20% of all adult interviews were completed by a proxy respondent. This could be attributed to the online form and greater ability for household members to complete it on behalf of the selected person. All proxy interviews that were completed without the selected adult being present were removed. This was because it would be difficult for questions in the NHS to be answered by another person without the selected adult being a present and active participant in the survey.</p>
Scope and coverage	<p>A sample representative of the Australian population. One adult aged 18 and over and one child aged 0–17 were randomly selected to complete individual questionnaires. The sample design of approximately 11,000 households is not sufficient to enable detailed analysis of state and territory estimates. The scope includes:</p> <p>Usual residents in Australia aged 0 and over living in private dwellings</p> <ul style="list-style-type: none"> • both urban and remote areas in all states and territories, except for very remote parts of Australia and discrete Aboriginal and Torres Strait Islander communities • members of the Australian permanent defence forces living in private dwellings and any overseas visitors who have been working or studying in Australia for the previous 12 months or more, or intend to do so. <p>The following people were excluded:</p> <ul style="list-style-type: none"> • visitors to private dwellings • overseas visitors who have not been working or studying in Australia for 12 months or more, or do not intend to do so • members of non-Australian defence forces stationed in Australia and their dependents • non-Australian diplomats, diplomatic staff and members of their households • people who usually live in non-private dwellings, such as hotels, motels, hostels, hospitals, nursing homes and short-stay caravan park (people in long-stay caravan parks, manufactured home estates and marinas are in scope) • people in very remote areas

			<ul style="list-style-type: none"> discrete Aboriginal and Torres Strait Islander communities households where all Usual Residents are under 18 years of age.
Geographic coverage			Both urban and remote areas in all states and territories, except for very remote parts of Australia and discrete Aboriginal and Torres Strait Islander communities.
Frequency/timing			<p>The 2020–21 NHS was conducted throughout Australia from August 2020 to June 2021. Previous surveys were conducted in 1989–90, 1995, 2001, 2004–05, 2007–08, 2011–12 and 2014–15 and 2017–18.</p> <p>The 2020–21 NHS data should be considered a break in time series from previous NHS collections (no survey was conducted in 2019–20) and used for point-in-time national analysis only.</p>
Basic collection count			Persons in 11,110 fully responding households.
Size			The 2020–21 NHS sample comprised 13,281 persons. The weighted estimate is 24,995.4 persons.
Collection management organisation			ABS.
Further information			National Health Survey: First Results methodology, 2020-21 financial year Australian Bureau of Statistics (abs.gov.au)
Priority information area	Risk factors	✓	<p>Cancer-related risk factors:</p> <p>110106. Skin Cancer</p> <p>110107. Breast Cancer</p> <p>110108. Cancer of female genital organs</p> <p>110109. Cancer of male genital organs</p> <p>Non-cancer-related risk factors:</p> <p>100101. Tuberculosis</p> <p>180702. Varicose veins</p> <p>180799. Other diseases of veins lymphatic vessels</p> <p>219999. Other infections of the skin and subcutaneous tissue</p> <p>210201. Dermatitis and eczema</p> <p>210301. Psoriasis</p> <p>220102. Arthritis – Rheumatoid</p> <p>281101. Burns & scalds</p>
	Presence of condition	✗	180501. Oedema is available.
	Treatment and management	✗	An item regarding whether receiving treatment for cancer is available (CNCRQ13), however there are no further items specifying the type of treatment.
	Individual impact	✓	Time off work or study, disability status, bodily pain, self-assessed health, physical activity, psychological distress.
	Population impact	✗	No data.
	Demographics of the study sample	✓	Age, sex, Indigenous status, place of usual residence, country of birth of respondent and year of arrival in Australia, country of birth of parents, main language spoken at home, proficiency in spoken English, educational qualification, occupation, marital status, household composition.
Bettering the Evaluation and Care of Health (BEACH) national study of general practitioner clinical activity			
Type of data source			Survey (national).

Brief description	<p>BEACH (Bettering the Evaluation and Care of Health) was a continuous national study of general practice activity in which ever-changing random samples of about 1,000 individual general practitioners (GPs) participated each year. Each GP recorded details of 100 consecutive encounters with consenting patients. BEACH began in April 1998 and closed in June 2016 after 18 years of continuous data collection. Since BEACH began it measured and reported major changes in Australian general practice including the changes in GP and practice characteristics, patients at encounters, reasons for encounters, problems managed, and the management provided.</p> <p>It included a component where additional questions were asked of patients in subsamples of encounters – the Supplementary Analysis of Nominated Data (SAND). Different questions were asked in each 5-week recording block. The SAND component asked more detailed questions for people with specific conditions.</p>
Purpose(s)	<p>The aims of BEACH were to:</p> <ul style="list-style-type: none"> • collect reliable and valid data about general practice which is responsive to the ever-changing needs of information users • establish an ongoing database of GP-patient encounter information • assess patient-based risk factors and the relationship these factors have with health service activity • provide accurate and timely data to a wide variety of users including government bodies, GP organisations, consumers, researchers and the pharmaceutical industry.
Collection methodology	<p>Data collection involved:</p> <ul style="list-style-type: none"> • random GP samples were supplied by the Australian Government Department of Health and Aged Care • each year, BEACH involved a new random sample of about 1,000 GPs • each GP recorded details of about 100 doctor–patient encounters of all types • the GP sample was a rolling (ever-changing) sample, with about 20 GPs participating in any one week, 50 weeks a year (with 2 weeks break over Christmas) • each GP could be selected only once per Quality Improvement & Continuing Professional Development (QI & CPD) Program triennium (that is, once in each 3-year period) • the encounter information was recorded by the GPs on structured paper encounter forms (including MBS/ Department of Veterans’ Affairs (DVA) item numbers) • GP participants also completed a questionnaire about themselves and their practice • all consultations that resulted in a management action were recorded.
Scope and coverage	<p>The source population included all vocationally registered GPs and all general practice registrars who claimed a minimum of 375 Medicare general practice items of service in the most recently available 3-month Medicare data period (which equates to 1,500 such claims in a year). This ensured inclusion of the majority of part-time GPs, while excluding those were not in private practice but claimed for a few consultations a year.</p>
Bettering the Evaluation and Care of Health (BEACH) national study of general practitioner clinical activity (continued)	
Geographic coverage	All states and territories, Australia.

Frequency/timing	The BEACH survey began in 1998 and was undertaken continuously with results released annually. BEACH was discontinued in 2016.		
Basic collection count	GP encounters.		
Size	Over the ten-year period 2006–07 to 2015–16, BEACH contained 971,178 records of encounters from 9,721 General Practitioners.		
Collection management organisation	Faculty of Medicine and Health, The University of Sydney.		
Further information	https://www.sydney.edu.au/medicine-health/our-research/research-centres/bettering-the-evaluation-and-care-of-health.html		
Priority information areas	Risk factors	✓	Known risk factors for the development of secondary lymphoedema are available (e.g. various cancers, venous diseases, cellulitis).
	Presence of condition	✓	K99012 – Lymphoedema A87048 – Lymphoedema; postmastectomy A87046 – Lymphoedema; postsurgical
	Treatment and management	✓	Treatments as well as referrals to specialists, allied health professionals, hospital admissions etc. will be available for those diagnosed with lymphoedema.
	Individual impact	✗	No data.
	Population impact	✗	No data.
	Demographics of the study sample	✓	Age, gender, postcode of residence, non-English-speaking background status, Aboriginal and Torres Strait Islander status, Australian Government concession card status.

Survey of Disability, Ageing and Carers, Australia (SDAC)	
Type of data source	Survey (national).
Brief description	<p>The SDAC collects national information on people with disabilities, older people (aged 65 and over) and carers of people with disability or a long-term health condition or older people.</p> <p>In the SDAC disability is defined as any limitation, restriction or impairment that restricts everyday activities and has lasted, or is likely to last, for at least 6 months. A carer is a person who provides any informal assistance (help or supervision) to people with disability or older people (aged 65 and over). The assistance must be ongoing, or likely to be ongoing, for at least 6 months.</p> <p>The SDAC collects data on prevalence of disability, long-term health conditions, main disabling conditions (the conditions causing the most problems), type of impairments and core limitations (self-care, mobility and communication), participation restrictions in schooling and employment, level of participation in cultural, sport, social and/ or community activities, need for and receipt of assistance, accessibility difficulties, the need for/ use of aids and equipment due to disability, discrimination and feelings of safety.</p>
Purpose(s)	<p>To measure the prevalence of disability in the Australian population and the need for support of older people and people with disability.</p> <p>To describe a demographic and social economic profile of the population with disability, older people and people providing care for them.</p>
Collection methodology	<p>The ABS had 2 different ways of collecting information depending on where people lived:</p> <ul style="list-style-type: none"> • household component: private dwellings such as houses, flats, home units, townhouses and self-care components of retirement villages, or • cared-accommodation component: hospitals, nursing homes, hostels and other homes for a period of 3 months or more. <p>The sample for the household component was selected at random using a multi-stage area sample of addresses from the ABS's Address Register. From 29 July 2018 to 2 March 2019, random personal interviews on age, disability and carers were conducted. Proxy interviews were conducted for those who could not give interviews. Trained interviewers visited the randomly selected households to conduct personal interviews. The interviewer first asked screening questions of a responsible adult to find out whether anyone in the household had a disability; was aged 65 or over; provided care to another person. Interviews with people receiving care were also used to identify carers in that household.</p> <p>Where possible, people with disability, aged 65 or over or primary carers had a personal interview. To be identified as a primary carer, a person had to be providing the most informal help with a core activity to a person with disability. Some people were not interviewed directly, but had questions answered on their behalf (a proxy interview). Proxy interviews were done for children under 15 years of age; 15-17-year-olds whose parent or guardian did not agree to them being personally interviewed; people unable to answer for themselves due to illness, impairment, injury or language problems.</p> <p>Cared accommodation sample was collected by contacting through letters all known health establishments that provide long-term cared accommodation. Health establishments providing cared accommodation to residents for at least 3 months could be selected in the sample. If a health establishment was selected, its contact person was asked to choose a random sample of occupants for the survey by following instructions the ABS provided. Instead of interviewers visiting health establishments to personally interview a selected number of occupants living in the health establishment, the contact officer who worked within the health establishment completed a separate questionnaire for each randomly selected occupant.</p> <p>The range of information collected was narrower than in the household component as some topics were not suitable for a contact officer to answer on behalf of occupants, or relevant to people in cared accommodation.</p>

Survey of Disability, Ageing and Carers, Australia (SDAC) (continued)			
Scope and coverage	The survey covers people in private and non-private dwellings, including people in cared accommodation establishments. The scope excludes: people living in <i>very remote</i> areas, discrete Indigenous communities, people whose usual residence is outside Australia, non-Australian diplomatic personnel and members of non-Australian defence forces (and their dependants) stationed in Australia. Population groups that are not enumerated for operational reasons include people in boarding schools, and gaols or correctional institutions.		
Geographic coverage	The data is available at the national level and at the state level for New South Wales, Victoria, Queensland and Western Australia. Some data are available for other states and territories, but this may be limited due to standard error and confidentiality constraints.		
Frequency/timing	The survey has been conducted 9 times: in 1981, 1988, 1993, 1998, 2003, 2009, 2012, 2015 and 2018.		
Basic collection count	Households, family, income unit, person, long-term health condition, restrictions, broad activities, specific activities, recipients of assistance, assistance providers.		
Size	The final sample size of the 2018 SDAC was 65,805 people, comprising 54,142 persons for the household component and 11,663 for the cared accommodation component.		
Collection management organisation	ABS.		
Further information	https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release		
Priority information areas	Risk factors	✓	Cancer-related: 203. Skin cancer 204. Breast cancer 205. Prostate cancer Non-cancer-related 101. Tuberculosis 1201. Skin and subcutaneous tissue infections 1202. Skin allergies (eczema and dermatitis) 1204. Scars
	Presence of condition	×	No data specific to lymphoedema.
	Treatment and management	×	No data.
	Individual impact	✓	Data items include disability status, core-activity restrictions (self-care, mobility and communication), schooling and employment limitations, housing, transport, difficulty and need for assistance with specific activities, difficulty and need for assistance with broad activities, ability to participate in cultural, sport, social and/ or community activities, discrimination, feelings of safety, patient experience, self-assessed health and mental wellbeing.
	Population impact	✓	Impact of the caring role on carers and their self-assessed health and mental wellbeing, the effect of the caring role on carers' financial situation.
	Demographics of the study sample	✓	Age, sex, country of birth, registered and social marital status, characteristics of child in family, standard relationship in household, year of arrival in Australia, proficiency in spoken English, main language spoken at home, Indigenous status, state/ territory of usual residence, remoteness area, household and family structure, income, educational attendance and attainment, housing tenure type.

Longitudinal surveys

45 and Up Study	
Type of data source	Longitudinal survey (NSW).
Brief description	<p>The 45 and Up Study is a longitudinal cohort study of people from New South Wales (NSW). It follows the health of participants to examine which factors are associated with good or poor health as people age. Survey responses are linked to other health databases, to explore a broad range of health issues including diabetes, cancer, obesity, mental health, environmental health, and health service access and equity.</p> <p>The study collects information about doctor-diagnosed asthma, breast cancer, prostate cancer, non-melanoma skin cancer, melanoma, stroke, heart disease, high blood pressure and diabetes with the addition of osteoarthritis in the follow-up questionnaire. Participants are able to nominate other important illnesses and answer questions on treatment, so other conditions may be noted.</p>
Purpose(s)	To develop a research resource to boost understanding of how Australians are ageing. This will answer important health and quality-of-life questions and help manage and prevent illness through improved knowledge of health.
Collection methodology	<p>Potential participants were randomly sampled from the Medicare Australia database (approximately 50% of the NSW population) and mailed a study questionnaire and information leaflet. Individuals from rural areas and those aged 80 and over were oversampled.</p> <p>Recruitment commenced in February 2006, when more than 36,000 participants joined the study. By 2020, all participants had received 3 extensive surveys (at least one every 5 years). The 85,000 participants who received their follow up surveys in 2020 also received questions about the impact of COVID-19.</p> <p>Information available through data linkage includes: past and current health, medication, treatment, diagnostics, health service use from the MBS and PBS databases, hospitalisation data from the NSW Admitted Patients Data Collection (APDC) (with details of patterns of care), the NSW Emergency Department Data Collection, aged care and mortality data.</p> <p>The data also contain information on biospecimens to explore phenotypes, genotypes, lifestyle factors, disease, and treatments.</p>
Scope (theoretical coverage of relevant population) and coverage (actual)	The NSW population aged 45 or over, with a higher likelihood of selection for those in rural areas and those aged 80 and over. The study recruited more than 250,000 men and women aged 45 or over from the NSW general population. Of those, approximately 18% responded.
Geographic coverage	NSW.
Frequency/timing	Ongoing survey. 2006–2009 for the baseline survey and 2012–15 for the first follow-up survey (Wave 2). Wave 3 was completed in 2020. Data linkage began in 2008 and includes data before the survey period. By 2020, all participants had received 3 extensive surveys (at least one every 5 years).
Basic collection count	Persons.

45 and Up Study (continued)		
Size	<p>267,153 people completed baseline questionnaire between 2006 and 2009. Of these, 142,548 participants completed a questionnaire at the first follow-up (Wave 2; 2012–15). In 2020, around 85,000 participants received follow-up surveys including questions about the impact of COVID-19.</p> <p>In 2020–21, the new COVID Insights Surveys commenced in June 2020, recruiting a sample of 32,000 study participants from 85,000 participants from the 45 and Up Study to complete short online surveys about the impact of the pandemic. Two fast-turnaround surveys were completed in 2020–21, and 2 more were completed late 2021.</p>	
Collection management organisation	The Sax Institute.	
Further information	https://www.saxinstitute.org.au/our-work/45-up-study/for-researchers/	
Priority information areas	Risk factors	✓ <p>Baseline, Wave 2 and Wave 3</p> <p>evertoldmelanyes – Has a doctor ever told you that you have melanoma?.</p> <p>evertoldprostateyes – Has a doctor ever told you that you have: Prostate Cancer? (male only).</p> <p>evertoldbreastyes – Has a doctor ever told you that you have: Breast cancer? (female only).</p> <p>evertoldothercatype – Has a doctor ever told you that you have other cancer - type of cancer?</p> <p>MBS data: A number of procedures involving the dissection or excision of lymph nodes are risk factors for the development of secondary lymphoedema. See Appendix C.</p>
	Presence of condition	✓ <p>Wave 3</p> <p>fup2_evertoldlymphoyes – Ever told by a doctor that have: Lymphoedema?</p> <p>fup2_evertoldlymphoage – Age when condition first found: Lymphoedema?</p> <p>Due to the low uptake of invited participants (18%) the survey sample is not representative of the NSW population. It is not recommended that prevalence or incidence estimates be generalised to the NSW or national population. A comparison between the 45 and Up Study and the NSW Population Health Survey using weighting to the NSW population showed that differences occurred in prevalence of key health variables between the 2 studies (Mealing et al. 2010).</p>
	Treatment and management	✓ <p>45585 – Liposuction (suction assisted lipolysis) to one regional area (one limb or trunk), other than a service associated with a service to which item 31525 applies, if:</p> <p>(a) the liposuction is for:</p> <p>(i) the treatment of Barraquer-Simons syndrome, lymphoedema or macrodystrophia lipomatosa; or</p> <p>(ii) the reduction of a buffalo hump that is secondary to an endocrine disorder or pharmacological treatment of a medical condition; and</p> <p>(b) photographic and/or diagnostic imaging evidence demonstrating the clinical need for this service is documented in the patient notes (Anaes.)</p> <p>45048 - lymphoedematous tissue or lymphangiectasis, of lower leg and foot, or thigh, or upper arm, or forearm and hand, major excision of (Anaes.) (Assist.)</p>
	Individual impact	✓ <p>Self-rated quality of life, functional capacity, level of psychological distress. No data are available on the type of disability.</p>
	Population impact	✓ <p>Cost data are available from the linked data sources: the MBS, PBS, NSW APDC and NSW Emergency Department Data Collection data sets.</p>
	Demographics of the study sample	✓ <p>Age, postcode, education level, ancestry, country of birth, year of arrival in Australia, language spoken at home, Indigenous status, housing type, relationship status, household income, employment, social capital and private health insurance.</p>

Australian Longitudinal Study on Women's Health (ALSWH)	
Type of data source	Longitudinal survey (national).
Brief description	The ALSWH assesses women's physical and mental health, as well as psychosocial aspects of health (such as socio-demographic and lifestyle factors) and their use of health services.
Purpose(s)	To provide data about the health of women across the life span, in order to inform federal and state government health policy.
Collection methodology	<p>In April 1996, women in 3 birth cohorts (1973–78, 1946–51 and 1921–26) were selected from the Medicare database, which contains the name and address details of all Australian citizens and permanent residents. More than 40,000 agreed to take part in the project for at least 20 years. From 1996 to 2011, each age cohort was surveyed about once every 3 years by postal surveys. In 2011, the 1921–26 cohort began receiving a shortened survey every 6 months. In 2012–13 the ALSWH recruited a new cohort of young women, born 1989–94 (aged 18–23 at the time of completing the survey).</p> <p>Sampling from the population was random within each age group. Women from rural and remote areas were sampled at twice the rate of women in urban areas so that the numbers of women living outside major urban areas were large enough to allow statistical comparisons with women living in major urban areas.</p> <p>In addition to the main surveys, a variety of sub-studies are conducted targeting particular areas of health. These sub-study data include additional questionnaires and assess extra variables.</p> <p>The ALSWH has approval to access and link data to a number of de-identified national and state-based external data sets, including:</p> <ul style="list-style-type: none"> • Medical Benefit Schedule (MBS) • Pharmaceutical Benefits Scheme (PBS) • National Death Index • Perinatal data collections • Cancer registries • Admitted patients data collections.
Scope (theoretical coverage of relevant population) and coverage (actual)	<p>Australian women on the Medicare database aged 18–23, 45–50, 70–75 in 1996, and from 2013, women aged 18–23. A new cohort of young women, aged 18–23 (born 1989–95), was recruited in 2013. This cohort was surveyed annually from 2013–2018 (Surveys 1–6). Survey 7 was deployed in 2021 and surveys will follow a three-yearly cycle thereafter – scheduled for 2023.</p> <p>Retention:</p> <p>Cohort born in 1921–26 retained 12,432 women in the following surveys. The 1946–51 born cohort retained 13,714 women in the following surveys. The 1973–78 born cohort retained 14,247 women in the following surveys. The 89–94 born cohort retained 17,010 women in the next survey.</p>
Geographic coverage	There were 40,394 women in the original sample in 1996, which is broadly representative of the Australian female population. A new cohort of at least 14,000 women aged 18–23 was recruited in 2012 and 2013.
Frequency/timing	<p>Began in 1996 and to continue until at least 2019 (note: Survey 7 scheduled for 2023).</p> <p>From November 2011 the oldest cohort, women born 1921–26, have been surveyed at six-monthly intervals. A new cohort of young women, aged 18–23 (born 1989–95), was recruited in 2013. This cohort was surveyed annually from 2013 to 2018 (Surveys 1–6). Survey 7 was deployed in 2021 and surveys will follow a three-yearly cycle thereafter.</p>

Australian Longitudinal Study on Women's Health (ALSWH) (continued)		
Basic collection count		Female persons.
Size		<p>The most recent surveys had the following survey sizes:</p> <ul style="list-style-type: none"> • 1989–95 cohort: In 2012–13 more than 17,000 women aged 18–23 • 1973–78 cohort in 2015: 7,186 • 1946–51 cohort in 2013: 9,151 • 1921–26 cohort in 2011: 4,055 <p>From November 2011, the 1921–26 cohort has undertaken 6-monthly surveys. Survey 6 in 2018 had 30,421 participants.</p>
Collection management organisation		The University of Newcastle and the University of Queensland, funded by the Department of Health and Aged Care.
Further information		https://www.alswh.org.au/
Priority information areas	Risk factors	<p>✓</p> <p>MEDH-560: Age first diagnosed: Rheumatoid arthritis? MEDH-571: Age first diagnosed: Thrombosis? MEDH-585: Have you ever been diagnosed with or treated for cervical cancer? MEDH-588: Have you ever been diagnosed with or treated for breast cancer? MEDH-385: Have you ever been diagnosed with or treated for other cancer (text response)?</p> <p>Further information on risk factors available via data linkage.</p>
	Presence of condition	<p>✓</p> <p>Available via data linkage.</p>
	Treatment and management	<p>✓</p> <p>Available via data linkage.</p>
	Individual impact	<p>✓</p> <p>Activity of daily living, difficulty with activities and need for assistance, physical functioning, social functioning, self-reported wellbeing using the SF-36.</p>
	Population impact	<p>✓</p> <p>Linked data from the Medicare (MBS and PBS) databases.</p>
	Demographics of the study sample	<p>✓</p> <p>Age, sex, country of birth, language spoken at home, education, employment, family composition, area of residence, state of residence, socioeconomic status, remoteness, income, how women manage on their available income, time use (including paid and unpaid work and family roles) and life stages and key events (such as childbirth, divorce, death of a spouse). Linked data from the perinatal data collections.</p>

Busselton Healthy Ageing Study (BHAS)	
Type of data source	Cross-sectional community-based prospective cohort study with planned longitudinal follow-up.
Brief description	<p>Since 1966, the Shire of Busselton in Western Australia has undertaken a number of cross-sectional population surveys. These have been grouped together as the 'Busselton Health Studies'.</p> <p>The BHAS will enable a thorough characterisation of multiple disease processes and their risk factors within a community-based sample of individuals to determine their singular, interactive and cumulative effects on ageing. The project will provide novel cross-sectional data and establish a cohort that will be used for longitudinal analyses of the genetic, lifestyle and environmental factors that determine whether an individual ages well or with impairment.</p> <p>Phase 1 of the BHAS is a cross-sectional study of community-dwelling adults, born 1946 to 1964 and randomly selected from the shire electoral roll. Longitudinal follow-up of the same cohort is planned every 3–5 years (Phase 2).</p>
Purpose(s)	The general aim of the BHAS is to identify the cumulative effects of disparate illnesses that constitute the burden of disease that impacts on healthy ageing, starting with a detailed assessment of physical function, cognitive performance and quality of life in 'baby boomers'.
Collection methodology	<p>All non-institutionalised baby boomers who currently live in the shire and listed on the electoral roll are eligible to participate. Order of invitation to participate is randomised, with recruitment efforts focused upon sequential 10% sample draws. Contact with participants is by a letter of introduction, followed by a phone call to invite them to attend the testing centre for a four-hour appointment. Addresses are obtained from the electoral roll and phone numbers are obtained from local residential and business directories.</p> <p>The study protocol involves a detailed, self-administered health and risk factor questionnaire and a range of physical assessments including body composition and bone density measurements, cardiovascular profiling (blood pressure, ECG and brachial pulse wave velocity), retinal photography, tonometry, auto-refraction, spirometry and bronchodilator responsiveness, skin allergy prick tests, sleep apnoea screening, tympanometry and audiometry, grip strength, mobility, balance and leg extensor strength. Cognitive function and reserve, semantic memory, and pre-morbid intelligence are assessed.</p> <p>Participants provide a fasting blood sample for assessment of lipids, blood glucose, C-reactive protein and renal and liver function, and RNA, DNA and serum are stored. Clinically relevant results are provided to all participants.</p>
Scope (theoretical coverage of relevant population) and coverage (actual)	<p>The Busselton Shire comprises about 1.25% of the West Australian population (25,355 people according to the 2006 Australian Census) and a total of 6,690 adults born from 1946 to 1964 are registered on the 2010 electoral roll in the region, with 48.4% being male and an average of 352 individuals per year of birth group.</p> <p>Phase 1 of the BHAS commenced mid-2010 and ran until 2013. Based on current recruitment progress and participation rates, it is anticipated that approximately 4,000 participants will be recruited and tested (59% of those listed on the electoral roll). BHAS Phase 1 had 5107 participants.</p> <p>Phase 2: The Busselton Baby Boomer Study is under way during the period 2016–22 with a 5-year follow up.</p> <p>2020–2023: The Busselton Respiratory Study (BRS): Phenotypes of airway disease in the general population. The study protocol includes a comprehensive range of lung function and symptom measures and aims to recruit over 3000 adults from the Busselton community.</p>
Geographic coverage	Shire of Busselton, Western Australia.

Busselton Healthy Ageing Study (BHAS) (continued)			
Frequency/timing	2010–2015: The Busselton Healthy Ageing Study. Phase 1 completed. 2016–2021: The Busselton Baby Boomer Study. Phase 2 completed. 2020–2023: The Busselton Respiratory Study (BRS): Phenotypes of airway disease in the general population		
Basic collection count	Persons.		
Size	Over 5100 adults born between 1946 and 1964.		
Collection management organisation	The Busselton Population Medical Research Institute.		
Further information	http://bpmri.org.au/		
Priority information areas	Risk factors	✓	A number of cancers collected in the free-response section of the survey, including: <ul style="list-style-type: none"> • melanoma • cervical cancer • breast cancer • prostate cancer.
	Presence of condition	✗	No information specific to lymphoedema.
	Treatment and management	✗	No information specific to lymphoedema.
	Individual impact	✓	Quality of life, physical activity and sedentary behaviour, social inclusion and community values, mental health.
	Population impact	✗	No data.
	Demographics of the study sample	✓	Age, sex, marital status, ancestry/ethnicity, highest education level obtained and age at completion, current and previous occupational history (including years spent in longest occupation and exposure to dust), household income, dwelling type, years lived at current dwelling and occupancy status.

Registry-based data sources

Australian Cancer Database (ACD)	
Type of data source	National database
Brief description	<p>The Australian Cancer Database (ACD) contains data about all new cases of cancer diagnosed in Australia since 1 January 1982, excluding basal and squamous cell carcinomas of the skin.</p> <p>Cancer is a notifiable disease in all Australian states and territories. The 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 the data, notifies the registries of inter-state duplicates and produces the ACD.</p>
Purpose(s)	<p>To ensure evidence-based statistics are provided in order to measure the overall cancer incidence, projections, survival and prevalence within Australia since 1982.</p> <p>To provide researchers a holistic understanding surrounding the prevention, treatment and detection of multiple malignant cancers.</p> <p>Provide internal and external stakeholders with national cancer statistics through AIHW publications.</p>
Collection methodology	<p>The data collection process occurs through state and territory cancer registries. Information is provided to cancer registries by various notifiers including:</p> <ul style="list-style-type: none"> • hospitals • pathology laboratories • radiotherapy laboratories • registries of births, deaths and marriages.
Scope (theoretical coverage of relevant population) and coverage (actual)	<p>The ACD is a comprehensive data set which stores data about all new cases of cancer diagnosed in Australia since 1 January 1982. The following exclusions apply to the ACD:</p> <ul style="list-style-type: none"> • Not all tumours diagnosed as benign, of borderline malignancy or in situ are included. • Only primary cancers are included. Therefore, recurrences and metastases are not included. • Basal cell carcinomas and squamous cell carcinomas are not included.
Geographic coverage	All states and territories.
Frequency/timing	State and territory cancer registries provide data annually – from 1982.
Basic collection count	Projected and actual count of new cancer cases within Australia.
Size	The projected count of new cancer cases within Australia in 2022 was 162,163. At the end of 2017, there were around 470,000 people living who had been diagnosed with cancer in the previous 5 years (2013–2017), and around 1,224,000 people living who had been diagnosed with cancer in the previous 36 years.
Collection management organisations	State and territory cancer registries and the AIHW.
Further information	<p>https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/data</p> <p>https://www.aihw.gov.au/about-our-data/our-data-collections/australian-cancer-database</p>

Australian Cancer Database (ACD) (continued)

Priority information areas	Risk factors	✓	ICD-10 cancer diagnoses.
	Presence of condition	✗	No information specific to lymphoedema.
	Treatment and management	✗	No data.
	Individual impact	✓	Death.
	Population impact	✗	No data.
	Demographics of the study sample	✓	Sex, age, country of birth, address, postcode, statistical area, state, diagnosis age, month and year; Indigenous status.

General practice CIS data extraction data sources

MedicineInsight data	
Type of data source	Longitudinal general practice activity collected from clinical software.
Brief description	MedicineInsight was established by NPS MedicineWise in 2011, with core funding from the Australian Government Department of Health and Aged Care. In 2023, the Australian Commission on Safety and Quality in Health Care became the custodian of MedicineInsight. It collects general practice data to support quality improvement in Australian primary care and post-market surveillance of medicines and tests, and it continues to grow as a valuable resource for Australian longitudinal general practice research.
Purpose(s)	<p>MedicineInsight is the first large-scale, national primary care data program in Australia that extracts longitudinal patient information from the clinical software used in general practice.</p> <p>MedicineInsight achieves better health care for all Australians by:</p> <ul style="list-style-type: none"> • supporting quality improvement in participating general practices • supporting the safe use of new medicines • informing future policy and primary care research • supporting a sustainable Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Schedule (MBS).
Collection methodology	<p>De-identified data are extracted from the clinical information systems (CIS) that participating general practices use to manage patient records and write prescriptions. Data include information entered directly by GPs and practice staff as well as system-generated data such as the time and date that records are accessed.</p> <p>A whole-of-practice retrospective data collection is conducted when a practice joins MedicineInsight. Subsequent extractions take incremental data, enabling the development of a longitudinal database in which de-identified patients within practices can be tracked over time.</p>
Scope (theoretical coverage of relevant population) and coverage (actual)	<p>The 2019–20 data includes 458 general practices and 4,026 GPs nationwide, which corresponds to 5.6% of all Australian general practices and 10.7% of all Australian GPs. The distribution of GPs between state and territories is similar to the national coverage. Coverage in parts of very remote areas in Queensland and the Northern Territory is not as good due to the use of CIS systems that are not compatible with the MedicineInsight data extraction tool. There is funding to improve this coverage.</p> <p>In 2019–20 approximately 2.47 million patients were seen at least once by GPs in the participating practices. This represents 11.1% of all patients seen by GPs nationally.</p>
Geographic coverage	National.
Frequency/timing	Monthly longitudinal, de-identified, whole-of-practice data extracted from the CIS of consenting general practices across Australia.
Basic collection count	Patient encounters, practices, sites.
Size	<p>2019–20 data comprised:</p> <ul style="list-style-type: none"> • 458 general practices from 406 general practice sites • 4,026 unique GP providers • 13.3 million clinical encounters • 2.47 million patients eligible to be included in the report (patients with at least one clinical encounter during the study period and high-quality data).

MedicineInsight data (continued)		
Collection management organisation		Australian Commission on Safety and Quality in Health Care (ACSQHC)
Further information		Transition of Quality Use of Medicines programs Australian Commission on Safety and Quality in Health Care
Priority information areas	Risk factors	✓ A range of diagnoses that increase the risk of developing secondary lymphoedema are likely available. MBS item numbers are also available.
	Presence of condition	✓ Lymphoedema is available.
	Treatment and management	✓ Treatments as well as referrals to specialists, allied health professionals, etc. will be available for those diagnosed with lymphoedema. MBS items are also available.
	Individual impact	✗ No data.
	Population impact	✓ MBS billing information.
	Demographics of the study sample	✓ Age, year of death, sex, Indigenous status, state, remoteness, SEIFA decile, IRSAD decile and Primary Health Network (PHN).

POLAR data	
Type of data source	Routinely collected de-identified general practice data on behalf of Primary Health Networks (PHNs) – Victorian and NSW-based data set.
Brief description	<p>POLAR Explorer has been developed by Outcome Health specifically for use by general practice and PHNs. The system combines data extraction and reporting tools that enable analysis in a practical, user-friendly way.</p> <p>POLAR contains approximately 1,300 practices on the eastern border of Australia. Roughly 80% of participating practices have agreed to supply de-identified data snapshots for research through the POLAR tool.</p>
Purpose(s)	<p>POLAR Explorer GP, an in-practice auditing tool, allows practices to analyse their clinical and billing data to develop actionable insights about their patients and business. POLAR Explorer PHN is a web-based analysis portal, used by PHNs to conduct self-directed data analysis across a large range of de-identified data sets for population health planning, program development, evaluation and research.</p> <p>The POLAR System provides the benefits of Big Data to the health system, enhancing evidence-based decisions that can affect individuals through to broad population groups.</p> <p>POLAR collects data on behalf of PHNs for the purpose of:</p> <ol style="list-style-type: none"> Supporting clinical decision making at the practice level; Providing population health level data to PHNs; Facilitating PHN-approved research with tangible and translatable benefits to the general practice community.
Collection methodology	<p>The data is collected daily on behalf of PHNs from participating practices through an automated process. The data collected consists of approved items in the electronic medical record. This consists of administrative and clinical data.</p> <p>The data is de-identified at the point of collection so that no identifiable information is transferred from the practice.</p> <p>Various layers of mapping are applied to the data to improve interrogability and analysis. For example, diagnoses are mapped to SNOMED-CT, pathology tests are mapped to LOINC codes, medications mapped to ATC standard, etc.</p>
Scope (theoretical coverage of relevant population) and coverage (actual)	The data is collected on behalf of 5 PHNs (at the time of writing) covering large parts of Victoria and New South Wales. The combined population for the area covered by POLAR partner PHNs is approximately 6 million. POLAR contains (at the time of this report) 40 million records from 14.1 million unique patients.
Geographic coverage	Central and Eastern Sydney, Gippsland, Eastern Melbourne, South Eastern Melbourne and South Western Sydney PHNs.
Frequency/timing	<p>2010 onwards.</p> <p>Data retention period: 7 years for most data categories. All historical diagnoses are retained.</p>
Basic collection count	Activities, services, patients, practices, PHNs.
Size	<p>The data set consists of about 40 million patient records. We know there is patient duplication across practices. When we apply the SLK key, there are roughly 14 million unique patients.</p> <p>Patient postcode is captured as part of the medical record, so patients visiting from interstate will also be captured in this data set.</p>
Collection management organisation	Outcome Health.
Further information	www.polargp.org.au

POLAR data (continued)

Priority information areas	Risk factors	✓	A range of diagnoses that increase the risk of developing secondary lymphoedema are likely available. MBS items are also available.
	Presence of condition	✓	Lymphoedema is available.
	Treatment and management	✓	Treatments as well as referrals to specialists, allied health professionals, etc. will be available for those diagnosed with lymphoedema. MBS items are also available.
	Individual impact	✗	No data.
	Population impact	✓	MBS billing information.
	Demographics of the study sample	✓	Age, sex, country of birth, pension status, DVA status, Indigenous status, state, suburb, post code, PHN, ethnicity, marital status.

Other data sources

Lymphoedema Compression Garment Subsidy Scheme data			
Type of data source	Administrative (performance reporting).		
Brief description	Lymphoedema Compression Garment Subsidy schemes are funded by state and territory governments. Supplementary funding from the Australian Government is also provided to boost existing state and territory schemes to subsidise compression garments for lymphoedema and has contributed to the establishment of schemes in South Australia and Western Australia, while the state government funding focusses on delivering better services closer to home.		
Purpose(s)	The purpose of these schemes is to provide people living with lymphoedema, particularly those on pensions or health care cards, to access subsidised compression garments.		
Collection methodology	Varies by jurisdiction.		
Scope (theoretical coverage of relevant population) and coverage (actual)	People with lymphoedema who access the scheme in their jurisdiction (eligibility varies by jurisdiction); allied health professionals who treat lymphoedema.		
Geographic coverage	Access varies between states and territories depending on eligibility criteria.		
Frequency/timing	Annually. Historical data varies by when the scheme commenced in each jurisdiction.		
Basic collection count	<ul style="list-style-type: none"> • cost of the scheme • total number of clients accessing the scheme • total number of garments issued • number of off-the-shelf garments issued • number of clients receiving off-the-shelf garments • number of custom-made garments issued • number of clients receiving custom-made garments • number of new referrals to the scheme. 		
Size	N/A.		
Collection management organisation	Department of Health and Aged Care.		
Further information	State/territory health departments.		
Priority information areas	Risk factors	×	No data.
	Presence of condition	✓	Total number of clients accessing the scheme; number of clients receiving off-the-shelf garments; number of clients receiving custom-made garments; number of new referrals to the scheme.
	Treatment and management	✓	Total number of garments issued; number of off-the-shelf garments issued; number of custom-made garments issued.
	Individual impact	×	No data.
	Population impact	✓	Cost of the scheme.
	Demographics of the study sample	×	Location (state) only.

Appendix D: Use of Australian Government funding toward the compression garment subsidy scheme by state and territory

State/territory	Improved Access to Compression Garments Scheme description
Victoria	<p>The additional funding is being used to complement the existing Lymphoedema Compression Garment Program (LCGP) to assist Victorians living with lymphoedema by:</p> <ul style="list-style-type: none"> • expanding the types of garments to include adjustable wraps • changing number and combination of wraps for adults and children • strengthening quality assurance in standards accepted; and • removing requirement that beneficiaries are on a low to medium income. <p>The changed program was approved and implemented by the service provider effective 25 January 2021 following consultation with clinical advisors, including the Victorian Chief Allied Health Officer and other clinicians as part of an LCGP operational policy review.</p> <p>While this report is for the calendar year 2020, it is worthwhile noting that applications have doubled from 25 January 2021 to 25 March 2021 since implementation, particularly in relation to the made-to-measure and adjustable wraps.</p>
Tasmania	Not provided.
Queensland	<p>Supplementary funding provided by the Australian Government scheme supported the delivery of the already established program.</p> <p>Queensland Health support the implementation of the Guideline for Compression Garments for Adults with Lymphoedema: Eligibility, Supply and Costing to assist people with lymphoedema in accessing compression garments.</p> <p>Queensland Health supports the Compression Garment Service model that involves compression garment selection, fitting and monitoring provided by occupational therapists, physiotherapists and podiatrists (Queensland Health and non-Queensland Health) who have completed a formal lymphoedema training program (i.e. Level 1 or 2 course) such as the Australasian Lymphology Association (ALA) accredited lymphoedema training, and also those practitioners who have completed the Compression garment, selection, fitting and monitoring education package with professional support of lymphoedema therapists, supported by telehealth (where relevant), implementation resources and governance processes.</p>
South Australia	<p>In 2020, the focus for South Australia was on establishment of the Lymphoedema Compression Garment Subsidy Scheme, which was officially launched on 14 July 2020, by the South Australian Minister for Health and Wellbeing. This brought the state into alignment with other jurisdictions where subsidy schemes have been in place for some time.</p> <p>The scheme is supported through a funding commitment made by the Australian Government (\$694,000 between 2019–20 and 2023–24), as well as a contribution by the state government (\$747,000 between 2020–21 and 2022–23). In addition to this, the state government provided Local Health Networks with \$1.09 million activity funding to ensure any increased demand for lymphoedema services in the public sector could be met.</p> <p>Establishment of the scheme has meant South Australians can access subsidised garments across the state. Access is via eligible prescribers who have been approved as prescribers for the scheme.</p> <p>In addition, SA Health has supported delivery by providing additional activity funding to Local Health Networks to support anticipated increases associated with the delivery of the scheme. Some Local Health Networks have established new dedicated lymphoedema clinics such as in the Southern Adelaide Network.</p>

State/territory	Improved Access to Compression Garments Scheme description (continued)
Western Australia	<p>WA Health has used the additional funding from the Australian Government to establish a Prospective Surveillance Model of Care (PSM) Pilot Project for Early Detection of Lymphoedema. The project is being undertaken via the Sir Charles Gairdner Hospital (SCGH) Physiotherapy and Occupational Therapy departments in the North Metropolitan Health Service.</p> <p>The PSM pilot monitors pre-clinical changes of oedema to upper limbs post breast and regional nodal surgeries following a diagnosis of breast cancer, closely aligned with recent literature.</p> <p>In the 'traditional' pathway of lymphoedema surveillance, where physiotherapy surveillance occurs simultaneously with routine medical appointments at diagnosis/surgical planning pre-op, 2 weeks post-op, 12 and 24 months, patients recruited to the PSM pilot are also scheduled for regular surveillance at 3, 6, 9 and 18 months. Excluded patients will continue treatment in the 'traditional' model of care undertaken by the SCGH PT & OT department.</p> <p>In accordance with published evidence demonstrated by other breast cancer-related PSMs, the model of care in the pilot relies on objective parameters with lower thresholds. As the thresholds are lower, it is expected that patients will trigger referral to the pathway to early intervention for lymphoedema more frequently, eliciting an aggressive pre-clinical pathway, with the expected outcome of favourably altering the trajectory of onset of clinical disease with its associated morbidity, complexity and financial burdens.</p> <p>Patients diagnosed with pre-clinical lymphoedema will attend for an initial appointment, at 2 weeks and 4 weeks for re-assessment of pre-clinical status.</p> <p>'Pre-clinical' patients will receive compression class 2 garments (CCL2) immediately and will be expected to continue compliance with these garments for 4 weeks. They will receive education which includes skin and limb care, prevention strategies, self-management with lymphoedema massage techniques (self-MLD) and will be tutored carefully in the ongoing subjective surveillance of the limb for signs of progression to clinical lymphoedema to support self-management, assess fit & wearing schedule. Re-assessment of lymphoedema status occurs at 4 weeks.</p> <p>When the patient's objective data return to pre-threshold levels (= normal range), these patients will continue the PSM pathway of regular physiotherapy surveillance for a period of 2 years post-op, which amounts to 4 additional episodes of physiotherapy in their continuum of care.</p> <p>If the patient's objective measures do not return below sub-clinical levels, or progress to clinical lymphoedema Stage 1 or more, they will be discharged from the PSM pilot and treated in the 'traditional' model of care for clinical lymphoedema in the OT Lymphoedema Clinic.</p>
Northern Territory	<p>The Northern Territory (NT) has an existing comprehensive compression garment scheme with a limit of 2 garments per 6-month period, per affected limb. The Occupational Therapy (OT) Department at Royal Darwin and Palmerston Hospitals (RDPH) manages the scheme for the Top End Health Service (TEHS), and Allied Health at Alice Springs Hospital (ASH) manages the scheme for the Central Australia Health Service (CAHS).</p> <p>In order to ensure transparency and equity in expenditure of the scheme funding across the NT, a steering committee was formed in September 2020 with representation from the Department of Health and Aged Care, TEHS and CAHS. Although the NT has a comprehensive scheme in place, the steering committee identified key issues that affect the efficacy and timeliness of the NT scheme. These issues included:</p> <ul style="list-style-type: none"> • NT policy and data collection • human resource allocation and service location • training and retention of staff • equipment.

State/territory	Improved Access to Compression Garments Scheme description (continued)
NSW	<p>NSW Health will use its allocation of the Australian Government Lymphoedema Compression Garment and Allied Health Therapy funding to support service redesign and pilot an early intervention and prevention of chronic lymphoedema model of care for patients who have undergone surgery for breast cancer. This includes the surveillance, detection, and treatment of the early (sub-clinical) stages of lymphoedema with the prescription of temporary compression garments.</p> <p>Patients who undergo surgical removal of lymph nodes to treat breast cancer are at 20-30% risk of developing breast or upper limb lymphoedema. Surveillance and intervention for sub-clinical lymphoedema has been shown to reduce the risk to less than 10% for developing chronic lymphoedema.</p> <p>Patients can also experience musculoskeletal complications such as a decrease in shoulder range of motion and axillary webbing syndrome ('cording') which requires treatment from a qualified allied health professional (physiotherapist or occupational therapist).</p> <p>The early intervention and prevention of chronic lymphoedema pilot will provide the usual post-breast surgery care for musculoskeletal support and cording management, as well as surveillance, detection and treatment for sub-clinical lymphoedema, which has been shown to reduce the progression to chronic lymphoedema.</p>
ACT	<p>With the introduction of this funding under the scheme, the ACT Equipment Scheme (ACTES) Committee now includes a lymphoedema physiotherapist who provides clinical advice to the ACTES Committee on complex or applications that are high cost. This ensures the timely provision of products to these patients as the committee no longer needs to send queries back to the referring clinician if unsure about a prescription.</p> <p>Funding received under this agreement has contributed to improved data collection and data management, ensuring improved data for clinicians and service managers.</p>

Appendix E: State and territory compression garment schemes

State/territory	Garment Subsidy	Eligibility	Subsidy	Limit	Prescriber Guidelines/practitioner qualification
ACT	ACTES (ACT Equipment Scheme) , Canberra Health Services	<p>ACTES provides lymphoedema garments to people who have been medically assessed as having either primary or secondary lymphoedema.</p> <p>The following are the eligibility criteria to access lymphoedema compression garments under the ACT Equipment Scheme (ACTES), Canberra Health Services:</p> <ul style="list-style-type: none"> • Be a permanent Australian resident with a minimum of 6 months residency. • Be a permanent Australian and ACT resident with a minimum of 6 months residency. • Require assistance for a permanent disability or for a disability that has lasted for at least 2 years duration (as determined by the referring medical practitioner) or be frail aged person. • If a compensable client, agree to reimburse the ACT Government – Health Directorate in full upon settlement of the associated claim. • Under 16 years of age (required birth certificate on initial application). • Over 16 years of age; and with the following circumstances: <ul style="list-style-type: none"> ○ In receipt of a full Australian Government Centrelink Pensioner Concession Card in their own name, for the ACT; or ○ Hold a current valid Centrelink Health Care Card in their own name, for the ACT. • Clients are <u>not</u> eligible to access lymphoedema compression garments if they are: able to claim through their private health insurance; eligible to receive assistance from other government schemes such as the National Disability Insurance Scheme; inpatients at hospitals; and living in a residential aged care facility. 	100%	Only two (2) sets per condition of stockings or two Lymphoedema garments will be supplied within a six-month period to approved applicants. All applications exceeding \$2,000 are presented to the ACTES Advisory Committee for consideration for approval.	A completed ACTES application form is required from an authorised prescriber, which can be an occupational therapist, physiotherapist or nurse practitioner. Applications must be accompanied by a referral from a medical practitioner or specialist. A new ACTES application is required for any additional supply.

State/territory	Garment Subsidy	Eligibility	Subsidy	Limit	Prescriber Guidelines/practitioner qualification
Victoria	Lymphoedema compression garment program (LCGP)	<p>1) Permanent resident of Victoria or hold a Permanent Protection Visa 2) No other funding options 3) Not a resident in an Australian Government funded facility 4) Not an inpatient of a public hospital within past 30 days for condition related to lymphoedema 5) Not a current inpatient of a private hospital</p> <p>Additional Information Garments are available to people who:</p> <ul style="list-style-type: none"> • have been medically assessed as having either primary or secondary lymphoedema or sub-clinical lymphoedema • ATP has confirmed intended compliance with recommended use • Quality Standards compliance: <ul style="list-style-type: none"> – TGA registered compression garments that guarantee level of compression stated to evidence medical efficacy for treatment of lymphoedema – Supplier confirmation of garment compliance with any relevant International Standard and compression garment classification level (I – IV) – Standard 101 certification (Oeko Tex) where relevant – Priority of Access: <ul style="list-style-type: none"> • First time garment user • Children <18 years of age • VA&EP Priority of Access 	<p>Ready to Wear (RTW): Per set of garments per affected limb \$150 Made to Measure (M2M): Per set of garments per affected limb where RTW is not compatible with limb size/shape or compression class not available in RTW \$300 Adjustable Wrap System (AWS) kits: Per set of garments per affected limb \$150 Donner \$60</p>	<p>Adults – up to 4 sets of compression garments per year Child – 6 sets of compression garments per year Garments are available for limbs only Donner subsidy available as 'once off' only (where more than one item for the same limb is requested, the practitioner must confirm that each item is integral for the functionality of the other for the request to count as "one item")</p>	<p>Current general AHPRA registration as an occupational therapist OR physiotherapist OR registered nurse OR nurse practitioner OR medical practitioner AND ARE Eligible for membership as a Category 1 practitioner with the Australasian Lymphology Association (ALA) Current SWEAT ATP registration for relevant AT category</p>
New South Wales	EnableNSW	<p>1) Lymphoedema diagnosis 2) Be residing in NSW or Lord Howe Island 3) Be enrolled with Medicare 4) Require the assistive technology to support a health need 5) Require the assistive technology to remain independent at home 6) Not be eligible for compensation or damages 7) Not be eligible to receive assistive technology through any other government-funded program.</p>	<p>100% \$100 Co-payment required annually</p>	<p>Two sets of compression garments every 6 months</p>	<p>Lymphoedema therapist registered with the Australasian Lymphology Association – National Lymphoedema Practitioners Register – Level 1 (or eligible for registration)</p>

State/territory	Garment Subsidy	Eligibility	Subsidy	Limit	Prescriber Guidelines/practitioner qualification
Queensland	Compression garments for lymphoedema	<p>Queensland Hospital and Health Services provide compression garments for the treatment of lymphoedema to eligible Queensland permanent residents.</p> <p>Individuals are eligible if they meet all of the following criteria:</p> <ul style="list-style-type: none"> • A diagnosis of lymphoedema • Are aged over 16 years • Are an outpatient • Hold one of the following cards: <ul style="list-style-type: none"> - Centrelink Pensioner Card - Centrelink Health Care Card • Are Medicare eligible. 	100%	<p>Clients will be entitled to a maximum of two garments (per body part), in a single supply process and provided with a replacement time period of no less than 6 months. Replacement garments should be provided based on review of clinical need.</p>	<p>A clinician who meets the professional and training eligibility criteria as detailed below:</p> <ul style="list-style-type: none"> • Queensland Health physiotherapist, occupational therapist or podiatrist registered with Australian Health Practitioner Regulation Agency (AHPRA). <p>OR</p> <ul style="list-style-type: none"> • Non-governmental, community service organisation or private practitioner physiotherapist, occupational therapist, podiatrist registered nurse or medical doctor registered with Australian Health Practitioner Regulation Agency (AHPRA). <p>Training eligibility criteria</p> <ul style="list-style-type: none"> • Holds Level 1 lymphoedema training certificate or Foundational module plus relevant regional module/s accredited by the Australasian Lymphology Association (ALA), <p>and</p> <ul style="list-style-type: none"> • Eligible to register as an ALA Accredited Lymphoedema Practitioner, with recency of practice by demonstration of clinical experience in compression garment prescription within the previous two years, and • Continued professional development of 40 points in the previous two years as set out in the ALA Accredited Lymphoedema Practitioner Program Continuing Professional Development Policy. <p>OR</p>

					<ul style="list-style-type: none"> Completed the Compression garment, selection, fitting and monitoring education package https://ilearn.health.qld.gov.au/d2l/login with the support of a lymphoedema therapist including use of telehealth, implementation resources and governance processes.
South Australia	Lymphoedema Compression Garment Subsidy Scheme (CGSS)	<p>The scheme is accessible for people who meet all the following criteria:</p> <ul style="list-style-type: none"> have been diagnosed with primary or secondary lymphoedema by a Medical Practitioner have not received a set of garments in the past six months are not admitted as an inpatient at a hospital are a resident of South Australia are Medicare eligible are not eligible for garments through other sources/programs, i.e. National Disability Insurance Scheme, DVA Gold Card, work cover, private health insurance. 	100%	Two sets of garments (per body part) every 6 months	<p>To be considered as an approved prescriber under the scheme, clinicians will be an occupational therapist, physiotherapist, podiatrist or registered nurse who is:</p> <ul style="list-style-type: none"> a private clinician who holds a minimum Lymphoedema Training Certificate from an Australasian Lymphology Association (ALA) accredited training provider and; is registered with National Lymphoedema Practitioners Register (NLPR) or; is actively working towards NLPR registration and; is an experienced lymphoedema clinician with existing responsibility and expertise in garment measurement, prescription and fitting and; has evidence of the management of a minimum of 6 lymphoedema clients in the prior 12 months, or a clinician employed by SA Health prior to the roll out of the CGSS, in a role with clinical responsibilities in a lymphoedema specific clinical services and; has support from Line or Professional Manager confirming that the employee is an experienced lymphoedema clinician with existing responsibility and expertise in garment measurement, prescription and fitting and; has evidence of management of a minimum of 6

					<p>lymphoedema clients in the prior 12 months, or</p> <ul style="list-style-type: none"> • a clinician currently employed by SA Health who has successfully completed an SA Health approved training program. <p>From 1 July 2022, all clinicians applying for approval status will be required to be registered on the NLPR and will need to provide evidence of their registration after this date.</p>
Western Australia	CAEP (Community Aids and Equipment Programme)	<p>Compression garments for treatment of Lymphoedema are currently funded via the Community Aids and Equipment program (CAEP). To be eligible for CAEP patients must have a permanent disability and be a holder of either a Pensioner Concession Card, Health Care Card or Australian Government Seniors Health Card, or be a carer of a child with a permanent disability in receipt of a Carer Payment or be able to demonstrate financial hardship.</p>	Contact the WA Disability Services Commission for this information	Limit of 2 sets of garments annually	Public lymphoedema trained health professional
Tasmania	Tasmanian Lymphoedema Garment Scheme	<p>Financial assistance is available to people requiring compression garments to help manage lymphoedema and have a:</p> <ul style="list-style-type: none"> • Services Australia Pensioner Concession Card • Services Australia Health Care Card. <p>Note: For card holders of a DVA Pensioner Concession Card please consult the DVA.</p> <p>Patients must have a confirmed, or reasonably suspected, diagnosis of lymphoedema.</p> <p>Full criteria available here: Lymphoedema Clinic - Outpatient Clinics, Tasmanian Health Organisation - South (outpatients.tas.gov.au).</p>	Contact the relevant service for information: South: rhh.physiotherapy@ths.tas.gov.au North: lgh.ahs@ths.tas.gov.au North-West: burnie.physio@ths.tas.gov.au	Limit of 2 sets of garments per 6-month period	Public or private lymphoedema trained health professional
Northern Territory	Lymphoedema Compression Garment Subsidy, accessed through: The Occupational Therapy Department at Royal Darwin and Palmerston Hospitals (Top End Health Service [TEHS]) and Allied Health at Alice Springs	<p>The TEHS Lymphoedema Garment Subsidy Scheme eligibility criteria are as follows:</p> <p>Patients must live in the TEHS geographical area and have a diagnosis of lymphoedema or venous insufficiency.</p> <p>The eligibility criteria for the CAHS Lymphoedema Garment Subsidy Scheme are as follows:</p> <p>Patients who have had operative procedures for cancer involving resection/biopsy of lymph nodes or have had trauma causing injury to the lymph system and are considered at risk of lymphoedema, any patient who has a diagnosis of primary or secondary lymphoedema.</p> <p>Both TEHS and CAHS deliver the Lymphoedema Compression Garments Scheme via an outpatient service.</p>	100%	Limit of two garments per 6-month period, per affected limb.	Public or private lymphoedema trained health professional

	Hospital (Central Australia Health Service [CAHS]).				
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