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Data Resource Profile: The Life and health After Childhood cancer (LACE) project

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Abstract

Introduction

In Australia, around 85% of children survive childhood cancer. Yet, up to 80% of survivors experience subsequent adverse health conditions called late effects, largely attributed to cancer treatment. The LACE study is a population-based linked data resource that aims to facilitate the investigation of childhood cancer and its treatment and the impact on late effects for childhood cancer survivors.

Methods

The study links the Australian Childhood Cancer Registry to administrative cross-jurisdictional health and education data to enable ongoing follow-up of outcomes for childhood cancer survivors. The study population includes all Australian children aged less than 15 years, diagnosed with cancer 1983–2021, and comparison groups comprising siblings of childhood cancer patients and a random sample of children from the general population frequency matched by age, sex and residential location to cases.

Results

To date, the case cohort includes 25,226 children diagnosed with cancer, with longest follow-up to the age of 53 years. The most commonly diagnosed childhood cancers were leukaemia and related cancers ($n=8182$, 32.4%), followed by central nervous system and related cancers ($n=5850$, 23.2%), and lymphomas and reticuloendothelial neoplasms ($n=2568$, 10.2%). Overall, 16,314 (64.7%) children underwent chemotherapy, 5555 (22.0%) received radiotherapy and 7300 (28.9%) had surgical treatment for their cancer, with immunotherapy use reported for 641 (2.5%), hormonal therapy for 4549 (18.0%) and ancillary therapies for 2581 (10.2%). A total of 19,321 (76.6%) cases were alive at the end of the study.

Conclusion

This new comprehensive national data linkage resource represents a valuable asset that will facilitate research to identify the risk of late effects and effective follow-up care to inform counselling patients and their families, as well as guidelines, models of care and personalised follow-up care plans. Further, it will enable identification of inequities in healthcare access and outcomes across population sub-groups.

Keywords

late effects; treatment effects; chemotherapy; linked data; population-based; population data; outcomes

Key features

- The LACE study is a national and comprehensive population-based linked data resource, comprising administrative health and education data for a cohort of children diagnosed with cancer and matched sibling and population controls in Australia.
- This resource was created to enable ongoing follow-up of outcomes for childhood cancer survivors, establishing a valuable research resource to investigate the relationship between childhood cancer and its treatment and the impact on late effects that can impinge on quality of life for childhood cancer survivors.
- The study includes all Australian children (<15 years) diagnosed with cancer since 1983 and comparison groups comprising siblings of child cancer patients and a random sample of children from the general population frequency matched to cases. To date the case cohort includes 25,226 children diagnosed with cancer between 1983 and 2021, with the oldest participants followed up to the age of 53 years.
- The study links the Australian Childhood Cancer Registry, one of the most comprehensive population-based paediatric cancer registries in the world, to administrative cross-jurisdictional health and education data.
- The data resource comprises cancer registry, hospital and emergency services, mortality, births, education and child development, cancer screening, mental health, universal health insurance (Medicare) benefits and pharmaceutical benefits data.
- Proposals for collaborative projects from interested researchers can be submitted to the LACE Project Control Group at lance@uq.edu.au.

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Background

In Australia, the percentage of children surviving five years or more after being diagnosed with cancer has risen from approximately 25% in the 1960s, to around 85% by 2020 [1]. These improvements in survival combined with increasing incidence [2] have led to a growing population of childhood cancer survivors. Children diagnosed with cancer face the dual challenges of the cancer itself and its treatments at a time when their bodies are developing, and may live with the consequences of those life-saving treatments for many decades.

Childhood cancer survivors are at risk of adverse health conditions post treatment, often called 'late effects'. These may include subsequent primary cancers, organ dysfunction, decreased fertility, psychosocial problems and early mortality [3–9]. These late effects contribute to the profound impact of cancer on survivors' quality of life and wellbeing, long after their cancer has been successfully treated. A study of US patients who survived childhood cancer for ten years or longer found that nearly all survivors developed one or more chronic health conditions by the age of 50, and up to 80% experienced severe or life-threatening complications – twice as many as the general population [9]. Childhood cancer survivors have been found to be at increased risk of elevated distress and poor mental health, including depression, anxiety, post-traumatic stress disorder, and suicidal ideation [5–7], and report poorer educational outcomes and neurocognitive difficulties [8].

Late effects are caused largely by cancer treatment, particularly by the toxic effects of chemotherapy and radiotherapy, but also surgery, and may depend on the type, dose and site of therapy [3]. However, much of the evidence on late effects has lacked specific treatment information such as type and dose [10]. Further, evidence linking various treatments and late effects is largely based on self-reported data biased by low response rates [11, 12], and has seldom accounted for potential modifiers such as age at treatment, sex, and co-morbidities. Whether outcomes for childhood cancer survivors and healthcare utilisation differ by social determinants such as socioeconomic status and rurality has rarely been examined outside the United States. Additionally, many studies have considered late effects that occur five or more years post treatment, and few population-based studies have examined effects that occur earlier.

To reduce the incidence and severity of late effects, targeted care and follow-up of survivors is vital. Despite this, a previous survey found that almost two-thirds of survivors do not believe they are at risk of late effects, and over half were not engaged in follow-up care [13]. While there are guidelines for follow-up care, supporting evidence for these is variable [14, 15]. For example, systematic review has identified no studies that provide a population-wide or comprehensive evaluation of uptake of follow-up care, and health behaviours such as cancer screening, on late effects in childhood cancer survivors [13].

The LACE study

The LACE study is a population-based data linkage study of all Australian children diagnosed with cancer at less than 15 years of age since 1983, followed from the time of diagnosis until the

most recent data available. Data for cases obtained from the Australian Childhood Cancer Registry will be matched with siblings and controls from the general population to provide comparison groups. Records for cases and controls will be linked to administrative health and education data.

This comprehensive national data resource provides the first opportunity to build the evidence for follow-up care of treatment-related late effects as well as other proximal adverse outcomes (hereafter 'late effects') for children diagnosed with cancer at a population level. It ensures ascertainment and longitudinal follow-up of healthcare utilisation, a systematic description of the total health burden, and assessment of risk factors and causal pathways of outcomes [16], while minimising recruitment bias, loss to follow-up and recall bias which are common limitations of studies relying on follow-up, direct contact and self-report by participants.

The LACE study aims to investigate the relationship between cancer and its treatment and impact on late effects in childhood cancer survivors. Specifically, the study aims to: 1) describe the risk of late effects in childhood cancer survivors, compared to the risk of these outcomes in children without cancer; 2) evaluate the association between types of cancer treatment and risk of late effects, and 3) identify healthcare use and follow-up care associated with reduced risk of late effects and cost savings. The study will be used to inform service planning and the development of models of care to minimise the risk and severity of late effects in childhood cancer survivors.

Methods

Study population

The study population includes children diagnosed with cancer matched to sibling and population controls.

Childhood cancer group

The childhood cancer group will be identified from the Australian Childhood Cancer Registry (ACCR) [17], a national registry that includes all children residing in Australia who were diagnosed with cancer between 1 January 1983 and 31 December 2021, aged less than 15 years at the time of diagnosis.

In line with the International Classification of Childhood Cancer, Third Edition (ICCC-3) [18], childhood cancer refers to all malignant neoplasms as well as intracranial and intraspinal tumours of benign or uncertain behaviours.

Sibling comparison group

Siblings of children with cancer will be identified via birth registrations and/or perinatal records. The group will comprise all full biological siblings of childhood cancer cases and half biological siblings who share the same mother. The birth registration data can be used to identify both full and half biological siblings, while from the perinatal data it can only be determined that they were at least half biological siblings.

Population comparison group

A random sample of children from the general population who have not been diagnosed with cancer will be frequency matched to cases (up to 10:1), identified from the birth and/or perinatal records and matched by year and month of birth, sex, and postcode/Statistical Area at the time of diagnosis. If a sufficient number of matched individuals cannot be identified, criteria to select comparator children from a broader area of SA3 or SA4 have been specified, and in rare cases, if postcode/SA2 are not available, then only age and sex will be used.

Consumer involvement

The LACE study data resource will be guided by the input of consumer representatives and advocates, including a childhood cancer survivor, and a rural parent of a childhood cancer survivor. To ensure that research questions are focussed on clinical and consumer priorities, the study will engage with clinical and consumer stakeholders. This includes the Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG), the ANZCHOG National Patient and Carer Advisory Group, and the Redkite Lived Experience Advisory Group, which includes parents of children with cancer who will provide ongoing consumer input. The study's investigators are engaged with over 12 consumer and stakeholder groups, including Starlight Foundation, Ronald McDonald House Charities and Camp Quality.

Data sources

Records from the Australian Childhood Cancer Registry and comparison groups will be linked to data collections held by the Australian Government, and each of the eight Australian states and territories (New South Wales (NSW), Queensland (QLD), Victoria (VIC), Western Australia (WA), South Australia (SA), Tasmania (TAS), Northern Territory (NT) and the Australian Capital Territory (ACT)) (Table 1, Figure 1).

Childhood cancer data provided by the ACCR includes information on cancer diagnosis and stage at diagnosis [19, 21, 22], treatment information including chemotherapy, immunotherapy and hormonal therapy agents and other treatment modalities, mortality and subsequent primary cancers (Table 1). The ACCR contains information on all notified incident cases of cancer for children aged 0-14 years at diagnosis since 1983. This data has been collected from cancer registries in each Australian state and territory under appropriate ethics and legislative approvals. From these notifications, the ACCR contacts the treating hospital and conducts a medical record review to obtain detailed clinical information on diagnosis, stage [19, 21, 22], treatment and outcome for each childhood cancer case. Children registered in the ACCR are also matched annually against the Australian Cancer Database and the National Death Index to ensure that all subsequent primary cancers diagnosed at any age are recorded and that mortality/survivorship status is updated.

The linked health data collections include public and private admitted and outpatient hospital care, emergency department presentations, community mental health services, birth and perinatal data, and fact and cause of death data.

Cancer registry data includes information on cancer diagnoses for comparison groups, and cancer screening registries provide data on cervical, bowel and breast cancer screening participation. Information about primary and specialist health services accessed under Australia's national universal health insurance scheme is provided by the Medicare Benefits Schedule database, and information about use of prescription medicines by the Pharmaceutical Benefits Scheme database. Education data comprise results from the national assessment of early child development, the national literacy and numeracy assessment program for school-aged children, and senior secondary school performance. Information about the data collections included in the study is provided in Table 1, with further details about each collection available elsewhere [23]. Figure 2 lists study outcomes to be measured from each data collection. The temporal coverage of the datasets is shown in Figure 3.

Data governance

LACE is governed by an Operations Committee including researchers and stakeholders from The University of Sydney, The University of Queensland, and Cancer Council Queensland (the ACCR data custodian), which convenes monthly to guide operations.

The LACE Steering Committee comprises all study co-investigators and partner organisations, which include The University of Sydney, The University of Queensland, Cancer Council Queensland, ANZCHOG and the ANZCHOG National Patient and Carer Advisory Group, Royal Children's Hospital Melbourne, and children's cancer charities Redkite and Canteen.

Data linkage

The ACCR will be linked to state/territory data and national collections within each jurisdiction by their respective data linkage units, who will also identify comparison groups. National data collections will be sourced from the AIHW, and linked by the AIHW to the cohort for NSW, ACT, Queensland and Victoria.

Details of the data linkage process for this study are presented in Figure 1. Linkage uses probabilistic methods based on personal identifiers (name, address, data of birth), with unique project identifiers assigned to each person separately for state/territory-wise and national linkages to enhance privacy.

Results

To date, the case cohort includes 25,226 children diagnosed with cancer between 1983 and 2021 in Australia, with the oldest participants followed up to the age of 53 years. Key demographic and clinical information relating to the childhood cancer group are presented in Table 2.

Mortality and rates of receiving a second primary cancer diagnosis decreased over the study period. In total, 19,321 (76.6%) were alive at the end of the study. Overall, 630 (2.5%) of children diagnosed with cancer received a subsequent primary cancer diagnosis during the study

Table 1: Description of the data collections included in the LACE study

Data collection	State/territory coverage	Description	Key variables
National			
Australian Childhood Cancer Registry (ACCR)	All	Contains records of every child residing in Australia who is diagnosed with cancer at less than 15 years of age since 1983. Information is obtained from population-based cancer registries in each state and territory and from treating hospitals.	Demographic data, cancer diagnosis, stage at diagnosis [19, 21, 22], treatment, outcome including mortality and subsequent primary cancers occurring at any age. Treatment information includes chemotherapy agents, immunotherapy and hormonal therapy agents, dose and route, radiotherapy by site and dose, surgery by site and type and other treatments, such as bone marrow transplants, for the initial treatment plan.
Medicare Benefits Schedule (MBS)	All	Australia has universal health insurance for primary and specialist out-of-hospital care, with national data recorded in the MBS database. These data comprise processed claims for subsidised medical, specialist, nursing, allied health and diagnostic services by registered practitioners.	Date of service, item number of the claim (e.g. General Practitioner or specialist consultation, diagnostic test), provider number/postcode, fee.
Pharmaceutical Benefits Scheme (PBS)	All	The Australian government subsidises the cost of a wide range of prescription medicines. The PBS records dispensing of medications listed on the PBS schedule. Prior to 2012, this included medications for which a subsidy was paid. From April 2012 onwards all dispensed medications are included.	Medicine code, patient demographics, date of supply, prescriber type.
Medicare Consumer Directory (MCD)	All	Records place of residence over time to ascertain socio-demographic exposure and geographical area of residence	Place of residence (Statistical Area Level 2 [20] and/or postcode)
National Death Index (NDI)	All	Includes information on date and cause of death. Allows capture of death information for people residing in a different state to the time of recruitment, which is not captured in state and territory death registries.	Date of death, cause of death
Australian Cancer Database (ACD)	All	The ACD is a register of incident cancer cases since 1982. This will provide information on second primary cancer diagnoses for cases and cancer diagnoses for comparison groups.	Demographic, clinical and diagnostic information (type, site, morphology, spread, basis of diagnosis)
Australian Early Development Census (AEDC)	All	National assessment of early childhood development, conducted every third year for children in their first year of school. It is based on a 100-item checklist completed by teachers for each child.	Scores in five domains: (i) physical health/wellbeing; (ii) social competence; (iii) emotional maturity; (iv) language and cognitive skills; (v) communication skills and general knowledge

Table 1: Continued

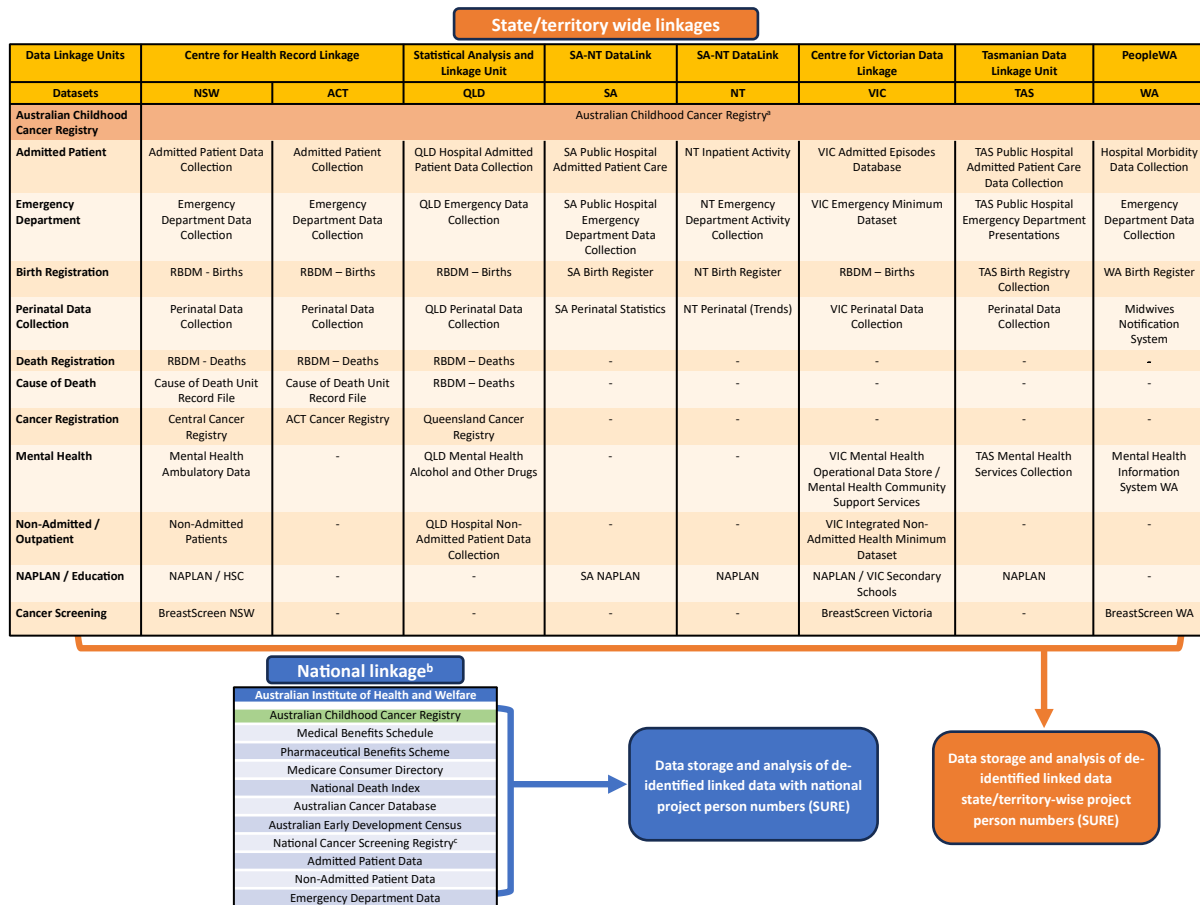
Data collection	State/territory coverage	Description	Key variables
National Cancer Screening Registry (NCSR)	All	Information on participation in the bowel and cervical cancer screening programs.	Date of screening, diagnosis
State/Territory Admitted Patient Data Collections (APDC)	All	A census of all public and some private hospital inpatient admissions. In addition to healthcare utilisation, comorbidities and outcomes, diagnosis and procedure codes provide details of cancer treatment beyond the initial treatment plan.	Diagnoses, procedures, dates of admission/ discharge/ procedures, patient demographics, insurance status
Emergency Department Data Collections (EDDC)	All	Records patient presentations to emergency departments of public and some private hospitals.	Timing, type and referral source of presentation, mode of arrival and separation, clinical diagnosis
Non-Admitted Patient Data (NAP)	NSW, ACT, QLD, VIC	Information on healthcare services provided in an outpatient setting at public hospitals.	Date of appointment, attendance, clinic specialty (e.g. oncology, cardiology, imaging, chemotherapy)
Mental Health Data Collections (MHDC)	NSW, QLD, VIC, TAS, WA	Records mental health contacts between clinicians and patients, including outpatient and outreach care and care to clients in community residential settings or receiving community support services.	Service provided, date of service, mental health diagnoses, provider identifier, provider role
Perinatal Data Collections (PDC)	All	Collection of all live births and stillbirths of at least 20 weeks' gestation or at least 400g birthweight	Date of birth, birthweight, gestational age at birth, maternal medical information, obstetric information, details about antenatal and birth care, details about labour and delivery, maternal and infant outcomes.
Birth Registrations (BR)	All	All births registered within the State and Territory Registries of Births, Deaths and Marriages.	Date of birth (baby, parent 1, parent 2), baby's sex, stillbirth flag, birth order.
Death Registrations (DR)	NSW, ACT, QLD	Deaths registered within the State and Territory Registries of Births, Deaths and Marriages. Deaths are registered in the state that they occurred.	Date of death, usual state of residence.
Cause of Death Unit Record File (COD)	NSW, ACT, QLD	Compilation of death records from the State and Territory Registries of Births, Deaths and Marriages and State and Chief Coroners through the National Coronal Information System.	Date of death, underlying and contributing causes of death, demographic and geographic information.
National Assessment Program – Literacy and Numeracy (NAPLAN)	All	Information on school performance, based on completion of the assessment program for grades 3, 5, 7 and 9.	Scores in five domains: reading, writing, spelling, language and punctuation, and numeracy; parental education and occupation, language spoken at home and exemption, absence and withdrawal from testing.

Continued

Table 1: Continued

Data collection	State/territory coverage	Description	Key variables
Senior Secondary School Data (SSD)	NSW, VIC	Senior secondary school data includes information on high school completion.	Performance band, secondary school results
BreastScreen	NSW, VIC, WA	Information on participation in the breast cancer screening program.	Date of screening, diagnosis

Figure 1: Data linkage process flow. State/territory datasets are linked by their respective data linkage units and Commonwealth data will be linked by the Australian institute of Health and Welfare (AIHW). De-identified linked state/territory data and national data are uploaded to the Secure Unified Research Environment (SURE) for data storage and analysis



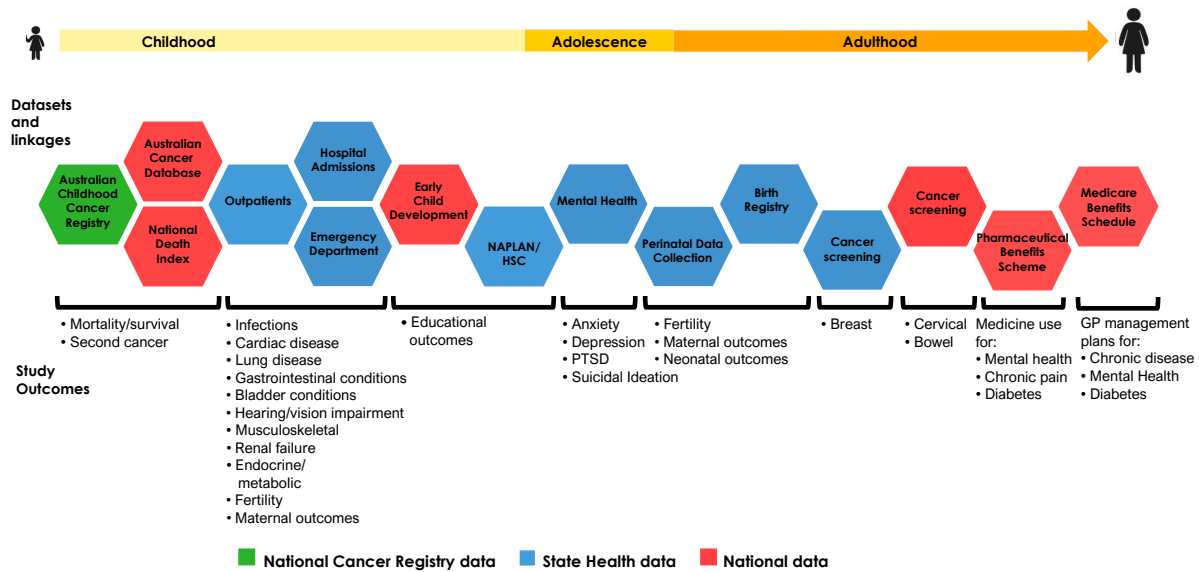
RBDM = Registry of Births, Deaths and Marriages, NAPLAN = National Assessment Program – Literacy and Numeracy, HSC = Higher School Certificate, NSW = New South Wales, ACT = Australian Capital Territory, QLD = Queensland, SA = South Australia, NT = Northern Territory, VIC = Victoria, TAS = Tasmania, WA = Western Australia. ^aSubset by state or territory. ^bNSW, ACT, Victoria and Queensland records will be linked to Commonwealth data by the Australian Institute of Health and Welfare (AIHW). ^cCervical and bowel screening programs.

period. Leukaemia and related cancers were the most commonly recorded cancer throughout the study period (overall $n = 8182$, 32.4%), followed by central nervous system and intracranial/intraspinal neoplasms ($n = 5850$, 23.2%), lymphomas and reticuloendothelial neoplasms ($n = 2568$, 10.2%), neuroblastoma and other peripheral nervous cell tumours ($n = 1611$, 6.4%) and soft tissue and other extra-osseous sarcomas ($n = 1426$, 5.7%). A total of 16,314 (64.7%) children underwent chemotherapy, 5555 (22.0%) received radiotherapy and 7300 (28.9%) had surgical treatment for

their cancer, with immunotherapy use reported for 641 (2.5%), hormonal therapy for 4549 (18.0%) and ancillary therapies for 2581 (10.2%).

Linkage of the ACCR cases to state/territory data and control selection has commenced or received approval to commence in the states/territories. Data linkage of the cohort (cases and comparison groups) to the national data collections is in preparation. It is estimated the complete cohort will contain approximately 300,000 data subjects (25,226 cases, ~25,000 sibling and ~250,000 population controls).

Figure 2: Data collections included in the LACE study, their associated study outcomes and ascertainment across the life course



Discussion

Data resource use

The LACE study aims to explore the relationship between cancer and its treatment and the subsequent development of late effects in childhood cancer survivors. Themes to be examined include mortality, chronic health conditions and psychosocial outcomes, subsequent primary cancers, fertility and perinatal outcomes, and education and developmental outcomes. Specific topics of study planned within the chronic health conditions theme include cardiac health, endocrinology (diabetes and metabolic syndrome), musculoskeletal outcomes (fractures, joint replacements), renal failure, hearing and vision loss, infection, gastrointestinal disorders and uterine disorders (Figure 2). Within each theme, we will examine incidence and relative risk of late effects in childhood cancer survivors compared to sibling and population groups as well as national age-sex specific population estimates. We will evaluate the association between the risk of late effects and key covariates, including type of cancer treatment, and examine patterns of health service utilisation and their association with adverse outcomes.

Strengths and limitations

A strength of this study is the use of population data and length of follow-up, from diagnosis for up to 39 years, to the age of 53 years, for the oldest cohort members. This ensures ascertainment and longitudinal follow-up of health service utilisation and health outcomes, and facilitates a systematic description of the total health burden, assessment of risk factors and causal pathways of outcomes [16]. This approach minimises selection bias, loss to follow-up and recall bias which are common limitations of studies relying on direct follow-up, consent and self-report of participants. The inclusion of matched comparison groups will facilitate comparison with similar peers without a history of childhood cancer to examine

the relative impact of the diagnosis and treatment on survivors, and allow inference of causality.

The inclusion of primary, secondary and tertiary healthcare data, and of education and child development data, allow comprehensive examination of a range of adverse outcomes with robust risk adjustment for co-morbidities and socioeconomic factors. The sociodemographic data and minimisation of selection bias on these factors due to the population-based nature of the resource allow research questions around variation and equity in uptake of follow-up, healthcare utilisation/access and outcomes for childhood cancer survivors. At a minimum, area-based measures of socioeconomic status and rurality are available on most data collections at each episode of care and will be used to explore potential inequities. This information is coded using Australian Bureau of Statistics Socioeconomic Index for Areas (SEIFA) and remoteness classifications and provided by data custodians in APDC, EDDC, PDC, NAP, MHAMB, CR, birth and death registrations, MBS, PBS, and NDI. We will also use additional individual-level measures of socioeconomic status, unique to some of the data collections, wherever possible. For instance, country of birth is available on datasets such as APDC, EDDC, PDC, and NAPLAN and parent's level of education and occupation is available in the NAPLAN data collections.

Due to the large number of datasets from multiple jurisdictions, there are naturally some variations in the date ranges of collections. For example, while the cohort includes children diagnosed with cancer from 1983, admitted patient data collections commence between 1983 (WA) and 2007 (Victoria), while emergency department data collections start between 2000 (NT, TAS) and 2008 (Queensland; Figure 2). This will impact the study periods and follow-up times for some outcomes in certain jurisdictions. Data imputation and other methods may be utilised to address these gaps.

It is worth noting that linked data are generally not collected for research purposes and can be lacking in clinical information and context. Admitted patient data contains only diagnoses relevant to the hospital admission, and reliability

Figure 3: Years of coverage of the datasets included in the LACE data resource, and the age of the oldest members of the cohort over the years of coverage



ACCR = Australian Childhood Cancer Registry, MBS = Medicare Benefits Schedule, PBS = Pharmaceutical Benefits Scheme, MCD = Medicare Consumer Directory, NDI = National Death Index, ACD = Australian Cancer Directory, AEDC = Australian Early Development Consensus, NCSR = National Cancer Screening Registry, APDC = Admitted Patient Data Collection, EDDC = Emergency Department Data Collection, NAP = Non-Admitted Patient Data, MH = Mental Health Ambulatory Data, MH-VIC = Victorian Mental Health Operational Data Store, Victorian Mental Health Community Support Services, PDC = Perinatal Data Collection, Births = Births Registry, Deaths = Deaths Registry, COD = Cause of Death Data, HSC = Higher School Certificate.

Table 2: Demographic and clinical characteristics of childhood cancer patients residing in Australia diagnosed between 1983-2021, aged less than 15 years of age at the time of diagnosis, relating to their first cancer diagnosis

Characteristics	Patients diagnosed 1983-1992 n (%)	Patients diagnosed 1993-2002 n (%)	Patients diagnosed 2003-2012 n (%)	Patients diagnosed 2013-2021 n (%)	Overall n (%)
Total	5245 (100.0)	6112 (100.0)	6697 (100.0)	7172 (100.0)	25,226 (100.0)
Age at diagnosis (yrs)					
< 1	482 (9.2)	630 (10.3)	725 (10.8)	720 (10.0)	2557 (10.1)
1 to 4	1967 (37.5)	2171 (35.5)	2506 (37.4)	2532 (35.3)	9176 (36.4)
5 to 9	1344 (25.6)	1536 (25.1)	1637 (24.4)	1873 (26.1)	6390 (25.3)
10 to 14	1452 (27.7)	1775 (29.0)	1829 (27.3)	2047 (28.5)	7103 (28.2)
State of residence ^a					
New South Wales	1763 (33.6)	2047 (33.5)	2165 (32.3)	2354 (32.8)	8329 (33.0)
Queensland	955 (18.2)	1189 (19.5)	1371 (20.5)	1541 (21.5)	5056 (20.0)
Victoria	1331 (25.4)	1496 (24.5)	1655 (24.7)	1796 (25.0)	6278 (24.9)
South Australia	426 (8.1)	453 (7.4)	472 (7.1)	464 (6.5)	1815 (7.2)
Western Australia	497 (9.5)	605 (9.9)	692 (10.3)	724 (10.1)	2518 (10.0)
Tasmania	128 (2.4)	164 (2.7)	150 (2.2)	118 (1.7)	560 (2.2)
Australian Capital Territory	96 (1.8)	106 (1.7)	115 (1.7)	111 (1.6)	428 (1.7)
Northern Territory	49 (0.9)	52 (0.9)	77 (1.2)	64 (0.9)	242 (1.0)
Diagnosis (ICCC-3) ^b					
I. Leukaemias, myeloproliferative and myelodysplastic diseases	1753 (33.4)	1930 (31.6)	2237 (33.4)	2262 (31.5)	8182 (32.4)
II. Lymphomas and reticuloendothelial neoplasms	516 (9.8)	599 (9.8)	650 (9.7)	803 (11.2)	2568 (10.2)
III. Central nervous system and intracranial/intraspinal neoplasms	1173 (22.4)	1458 (23.9)	1545 (23.1)	1674 (23.3)	5850 (23.2)
IV. Neuroblastoma and other peripheral nervous cell tumours	325 (6.2)	395 (6.5)	453 (6.8)	438 (6.1)	1611 (6.4)
V. Retinoblastoma	140 (2.7)	158 (2.6)	172 (2.6)	156 (2.2)	626 (2.5)
VI. Renal tumours	278 (5.3)	323 (5.3)	336 (5.0)	322 (4.5)	1259 (5.0)
VII. Hepatic tumours	49 (0.9)	92 (1.5)	114 (1.7)	96 (1.3)	351 (1.4)
VIII. Malignant bone tumours	232 (4.4)	242 (4.0)	262 (3.9)	291 (4.1)	1027 (4.1)
IX. Soft tissue and other extra-osseous sarcomas	334 (6.4)	339 (5.6)	382 (5.7)	371 (5.2)	1426 (5.7)
X. Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	172 (3.3)	234 (3.8)	277 (4.1)	259 (3.6)	942 (3.7)
XI. Other malignant epithelial neoplasms and melanomas	266 (5.1)	326 (5.3)	244 (3.6)	475 (6.6)	1311 (5.2)
XII. Other and unspecified malignant neoplasms	7 (0.1)	16 (0.3)	25 (0.4)	25 (0.4)	73 (0.3)
Subsequent primary cancer diagnosis					
Yes	265 (5.1)	207 (3.4)	126 (1.9)	32 (0.5)	630 (2.5)
No	4980 (95.0)	5905 (96.6)	6571 (98.1)	7140 (99.6)	24596 (97.5)
Status at end of study					
Alive	3235 (61.7)	4412 (72.2)	5433 (81.1)	6240 (87.0)	19,321 (76.6)
Dead	2010 (38.3)	1700 (27.8)	1264 (18.9)	932 (13.0)	5906 (23.4)
Treatment modalities					
Chemotherapy					
Yes	3355 (64.0)	4068 (66.6)	4709 (70.3)	4182 (58.3)	16314 (64.7)
No	1531 (29.2)	1721 (28.2)	1618 (24.2)	1499 (20.9)	6369 (25.3)
Radiation					
Yes	1812 (34.6)	1216 (19.9)	1408 (21.0)	1119 (15.6)	5555 (22.0)
No	3084 (58.8)	4560 (74.6)	4908 (73.3)	4535 (63.2)	17087 (67.7)

Continued

Table 2: Continued

Characteristics	Patients diagnosed 1983-1992 n (%)	Patients diagnosed 1993-2002 n (%)	Patients diagnosed 2003-2012 n (%)	Patients diagnosed 2013-2021 n (%)	Overall n (%)
Surgery					
Yes	1750 (33.4)	2023 (33.1)	1898 (28.3)	1629 (22.7)	7300 (28.9)
No	3224 (61.5)	3861 (63.2)	4498 (67.2)	4377 (61.0)	15960 (63.3)
Immunotherapy ^c					
Yes	<6 (0.1)	19 (0.3)	202 (3.0)	420 (5.9)	641 (2.5)
No/Unknown	>5239 (99.9)	6093 (99.7)	6495 (97.0)	6752 (94.1)	24,585 (97.5)
Hormone therapy ^c					
Yes	41 (0.8)	616 (10.1)	2082 (31.1)	1810 (25.2)	4549 (18.0)
No/Unknown	5204 (99.2)	5496 (89.9)	4615 (68.9)	5362 (74.8)	20,677 (82.0)
Ancillary therapy ^c					
Yes	<6 (0.1)	248 (4.1)	1124 (16.8)	1209 (16.9)	2581 (10.2)
No/Unknown	>5239 (99.9)	5864 (95.9)	5573 (83.2)	5963 (83.1)	22645 (89.8)
Transplant ^d					
Total	512 (9.8)	868 (14.2)	884 (13.2)	572 (8.0)	2836 (11.2)
Autologous	265 (5.1)	493 (8.1)	443 (6.6)	193 (2.7)	1394 (5.5)
Allogenic related donor	200 (3.8)	181 (3.0)	137 (2.1)	127 (1.8)	645 (2.6)
Allogenic unrelated donor	30 (0.6)	150 (2.5)	210 (3.1)	125 (1.7)	515 (2.0)
Allogenic unknown donor type	17 (0.3)	44 (0.7)	94 (1.4)	127 (1.8)	282 (1.1)
Treatment combinations					
Chemotherapy (C) only	1612 (30.7)	2655 (43.4)	3077 (46.0)	2866 (40.0)	10210 (40.5)
Radiation (R) only	201 (3.8)	124 (2.0)	99 (1.5)	110 (1.5)	534 (2.1)
Surgery (S) only	771 (14.7)	1067 (17.5)	991 (14.8)	844 (11.8)	3673 (14.6)
C + R	1047 (20.0)	618 (10.1)	833 (12.4)	622 (8.7)	3120 (12.4)
C + S	393 (7.5)	445 (7.3)	405 (6.1)	349 (4.9)	1592 (6.3)
R + S	256 (4.9)	134 (2.2)	94 (1.4)	91 (1.3)	575 (2.3)
C + R + S	294 (5.6)	335 (5.5)	378 (5.6)	281 (3.9)	1288 (5.1)
No C, R, or S	285 (5.4)	374 (6.1)	421 (6.3)	433 (6.0)	1513 (6.0)
Unknown	386 (7.4)	360 (5.9)	399 (6.0)	1576 (22.0)	2721 (10.8)

C = chemotherapy, R = Radiation, S = Surgery.

^aAt diagnosis.

^bDiagnosis group according to the International Classification of Childhood Cancer, Third Edition (ICCC-3) [18].

^cData for specific immunotherapy, hormonal therapy and ancillary therapy drug types may be incomplete for pre-2000 diagnoses.

^dIncludes bone marrow transplants, peripheral stem cell, cord blood and organ transplants.

Note: numbers may not add to column totals due to missing data.

Cells with fewer than six individuals are not reported.

may vary by condition and severity [24, 25]. Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data do not include clinical information such as diagnoses or indications, nor information about privately billed services or prescriptions, over the counter medications or medications provided in public hospitals.

Data access

Analysis datasets are de-identified and stored in remote-access, trusted research environments built for the analysis of linked health and health-related data. All state, territory and Commonwealth data will be accessed via the Sax Institute Secure Unified Research Environment (SURE [26]). Only

aggregated data will be published and no information will be published in a form that may identify individuals or from which an individual's identity could be reasonably ascertained.

Access to data is subject to data governance requirements and custodian approval. Proposed research should be within the scope of the study and requires collaboration and support by the LACE study researchers. Proposals for collaborative projects from interested researchers can be submitted to the LACE Project Control Group at lace@uq.edu.au.

Conclusions

The LACE study provides a comprehensive national data linkage resource that includes data on all children diagnosed

with cancer in Australia since 1983, matched siblings and population controls. ACCR data provides diagnosis and detailed treatment information, linked to health, education and child development data to the end of 2021. This population-level linked data resource ensures ascertainment and longitudinal follow-up of health service utilisation and health outcomes, while minimising selection and recall bias and loss to follow-up. This resource will facilitate research to identify the risk of late effects and effective follow-up care to better inform patient counselling, guidelines, models of care and personalised follow-up care plans, and to enable identification of inequities in healthcare access and outcomes across the life course.

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Ethics statement

Ethics approvals and waivers of consent were granted by the NSW Population and Health Services Research Ethics Committee (PHSREC) (2020/ETH02915 / 2020.87, 2022.STE.00153), the ACT Human Research Ethics Committee (ACT HREC) (#2022.STE.00153), the Human Research Ethics Committee of the Northern Territory (NT HREC) (#2023-4740), the Royal Children's Hospital Melbourne Human Research Ethics Committee (RCH HREC) (#HREC/86017/RCHM-2023), the University of Tasmania Human Research Ethics Committee (TAS HREC) (#30221), the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (CHQHHS HREC) (#HREC/04/QRCH/18), the Department of Health

WA Human Research Ethics Committee (WA HREC) (#RGS0000006307), and the Australian Institute of Health and Welfare Ethics Committee (EO2022/3/1149).

Conflict of interests statement

None to declare.

Publication consent

The authors consent to publish this paper. For details on how to access the data described in the paper, see Data Access and Data Availability Statement.

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Author contributions

NN, JP, PB, JA, and DY conceived the study, and developed the strategy and governance around the use of the data resource. NN, JP, PB, AC and LN sourced the data (sourcing is ongoing for some jurisdictions). AC conducted the data analysis. HB drafted the manuscript, with input from all authors. All authors approved of the final manuscript.

Data availability statement

The data are not publicly available due to privacy restrictions.

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HSC:	Higher School Certificate
ICCC-3:	International Classification of Childhood Cancer: Third Edition
LACE:	Life and health After Childhood Cancer
NSW:	New South Wales
NT:	Northern Territory
QLD:	Queensland
RBDM:	Registry of Births: Deaths and Marriages
SA:	South Australia
SURE:	Sax Institute Secure Unified Research Environment
TAS:	Tasmania
VIC:	Victoria
WA:	Western Australia

Abbreviations

ACCR:	Australian Childhood Cancer Registry
ACT:	Australian Capital Territory
AIHW:	Australian Institute of Health and Welfare
ANZCHOG:	Australian and New Zealand Children's Haematology/Oncology Group

