

EXTERNAL DATASETS - Information for users

Western Australia

Linkages of ALSWH survey data with the **Hospital Morbidity Data System (HMDS)**, **WA Cancer Registry and Midwives Notification System (MNS)** have been approved for the 1973-78, 1946-51 and 1921-26 cohorts. Linkages for the 1989-95 cohort are pending. Identifiers for all participants were provided to the WA Data Linkage Branch, with the exception of women who had explicitly **refused** consent to data linkages.

Description of datasets available:

Hospital Morbidity Data System (HMDS) – 1970 to current

Linked monthly

Comprised of around 20,000,000 electronic inpatient records back to 1970, snapshots of waitlist data dating back to 1991 and hospital survey data since 1993 (the Beds and Services Survey).

WA Cancer Registry - 1982 to current

Linked on a monthly basis

Includes all cases of cancer and some other neoplasm types

Includes details of non-WA deaths where known

Information supplied usually includes demographic data and one or sets of tumour details

Case-based, not event-based structure

Midwives Notification System (MNS) – 1980 to current

Linked monthly

30,000 births per year (including stillbirths)

- Includes births greater than 20 week's gestation or more than 400 grams in weight
- Information comes the Notification of Case Attended Forms (NOCA)
- Feeder Systems include
 - STORK (HIN System)
 - Ramsay System
 - South West System
 - SJOG System
 - Midwives Data Entry Package (HDWA)

[For further information on variables](#)

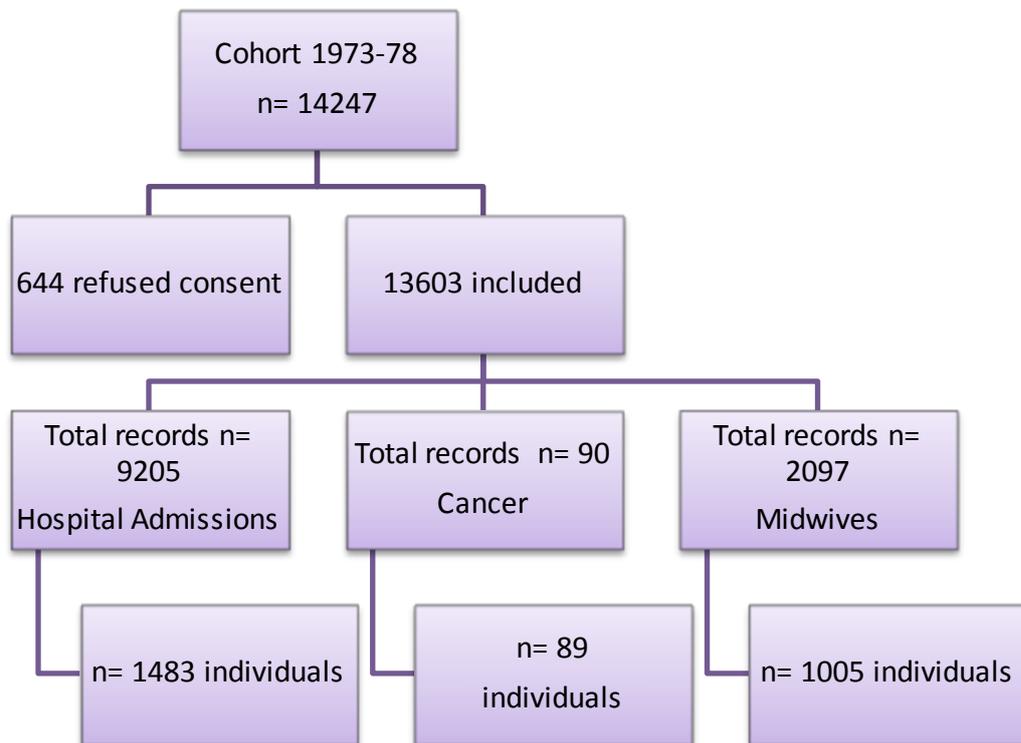


Figure 1 Total number of individuals and records per linked dataset for the 1973-78 cohort in Western Australia

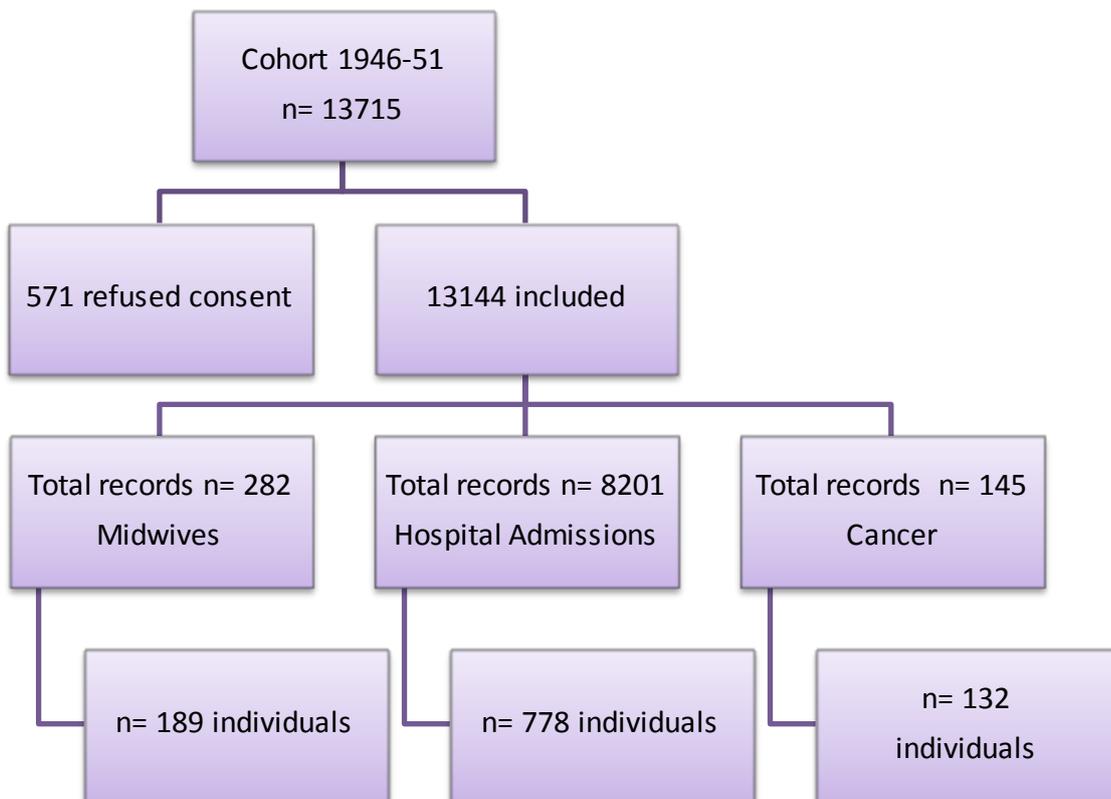


Figure 2 Total number of individuals and records per linked dataset for the 1946-51 cohort in Western Australia

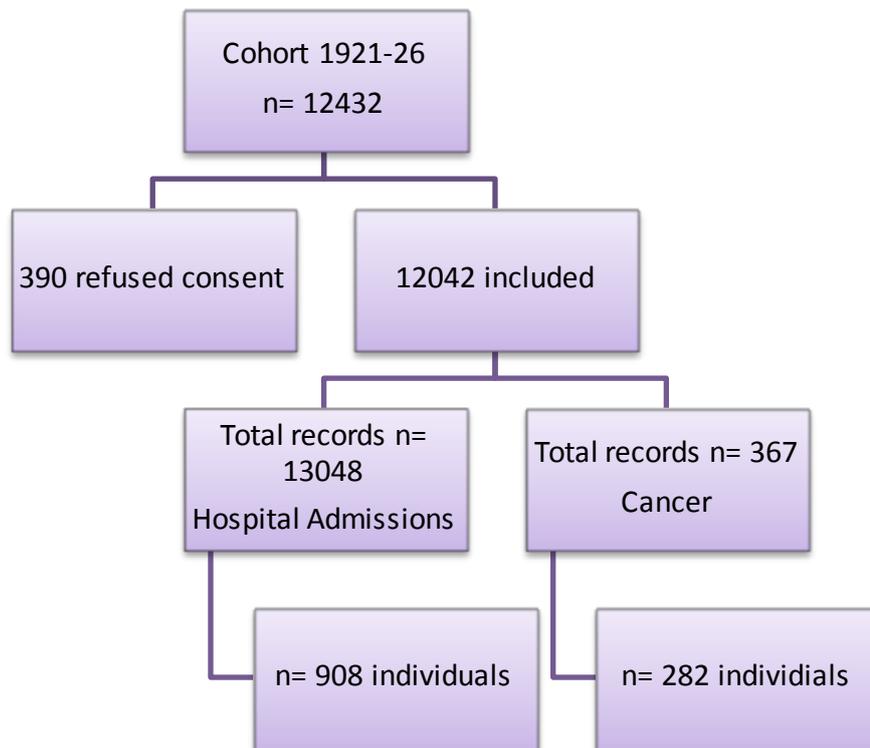


Figure 3 Total number of individuals and records per linked dataset for the 1921-26 cohort in Western Australia

New South Wales

Linkages of ALSWH survey data with the **Admitted Patients Data Collection (APDC)**, **NSW Cancer Registry and Perinatal Data Collection (PDC)** have been approved for the 1973-78, 1946-51 and 1921-26 cohorts. Linkages for the 1989-95 cohort are pending. Identifiers for all participants were provided to the Centre for Health Record Linkage (CHeReL), with the exception of women who had explicitly **refused** consent to data linkages.

NSW APDC- July 2000 to current

The NSW Admitted Patient Data Collection (APDC) records all inpatient separations (discharges, transfers and deaths) from all public, private, psychiatric and repatriation hospitals in NSW, as well as public multi-purpose services, private day procedure centres and public nursing homes. Patient separations from developmental disability institutions and private nursing homes are not included. Names are not available for admissions to private hospitals – while the CHeReL is able to link these records based on other demographic details, the linkage is likely to be less accurate. Caution must therefore be exercised in interpreting results where private hospital data are involved.

While the APDC includes data relating to NSW residents hospitalised interstate, names and addresses are not included on these records and therefore cannot be included in record linkage studies.

Public hospital APDC data are recorded in terms of episodes of care (EOC). An episode of care ends with the patient ending a period of stay in hospital (e.g. by discharge, transfer or death) or by becoming a different “type” of patient within the same period of stay. The categories of types of care are listed under the variable “Episode of care type”. For private hospitals, each APDC record represents a complete hospital stay. APDC records are counted based on the date of separation (discharge) from hospital.

NSW Central Cancer Registry – 1972 – current

The Central Cancer Registry (CCR) receives notifications of cancer in NSW. It is managed by the Cancer Institute NSW for the NSW Department of Health (DOH) and operates under the authority of the Public Health Act 1991. The Registry maintains a record of all cases of cancer diagnosed in NSW residents since 1972 and a record of all cases where a person has died from cancer from 1972 onwards. The CCR is a case-based registry in which all notifications relating to a particular cancer are linked to a single person. A cancer is the occurrence of a primary malignant neoplasm in an organ of a particular person. If the same person has another cancer, that cancer counts as a second case.

The CCR records new cancer cases but not cancer recurrences. Deaths are recorded for all people dying from cancer whose cancer was diagnosed when they were residing in NSW, even if the death occurs outside NSW. The data relate to invasive primary cancers diagnosed in NSW since 1972, and cancer deaths. It does not include skin cancers other than melanoma (e.g. basal cell carcinoma and squamous cell carcinoma are excluded).

Notification of malignant neoplasms and pre-malignant breast carcinoma and melanoma is a statutory requirement for public and private hospital, departments of radiation oncology, nursing homes, pathology laboratories, outpatient departments and day procedure centres. Mandatory pathology reporting has occurred since 1986. Data collected by the Central Cancer Registry includes personal identifiers and demographic information, brief clinical details describing the cancer and a record of at least one episode of care from a notifier. Similar details are supplied electronically by many hospitals. The data are supplemented by information from pathology reports and death certificates. In situ lesions for breast cancer and cutaneous melanoma are also routinely collected

Perinatal Data Collection (PDC) - 1987 to current

The NSW Perinatal Data Collection (formerly known as the Midwives Data Collection) is a population-based surveillance system covering all births in NSW public and private hospitals, as well as homebirths. The data collection has operated since 1987 but only continuously since 1990. The Perinatal Data Collection (PDC) is a statutory data collection under the NSW Public Health Act 2010.

The PDC encompasses all live births, and stillbirths of at least 20 weeks gestation or at least 400 grams birth weight. For every birth in NSW the attending midwife or medical practitioner completes a form (or its electronic equivalent) giving demographic, medical and obstetric information on the mother, and information on the labour, delivery and condition of the infant. Completed forms are sent to the Data Integrity and Governance Unit, Information Management and Quality, in the Health System Information and Performance Reporting Branch of the NSW Ministry of Health, where they are compiled into the PDC database. Around two-thirds of PDC notifications are received electronically from hospital obstetric information systems. There are several electronic systems that generate the PDC data including ObstetriX and Cerner.

The information sent to the NSW Ministry of Health is checked and compiled into one statewide dataset. One record is reported for each baby, even in the case of a multiple birth. The PDC was revised in 1998, 2006 and 2011. The PDC includes notifications of births which occur in NSW which includes women whose usual place of residence is outside NSW and who give birth in NSW; it does not receive notifications of interstate births where the mother is resident in NSW. The collection is based on the date of birth of the baby.

[For further information on variables](#)

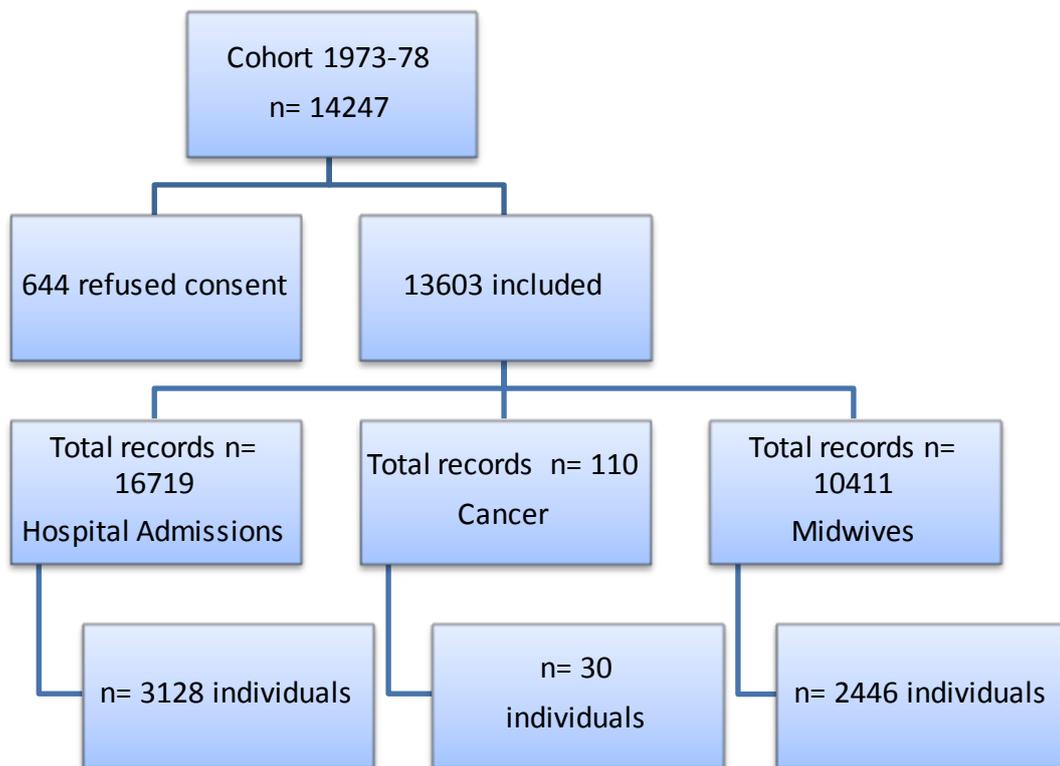


Figure 4 Total number of individuals and records per linked dataset for the 1973-78 cohort in New South Wales

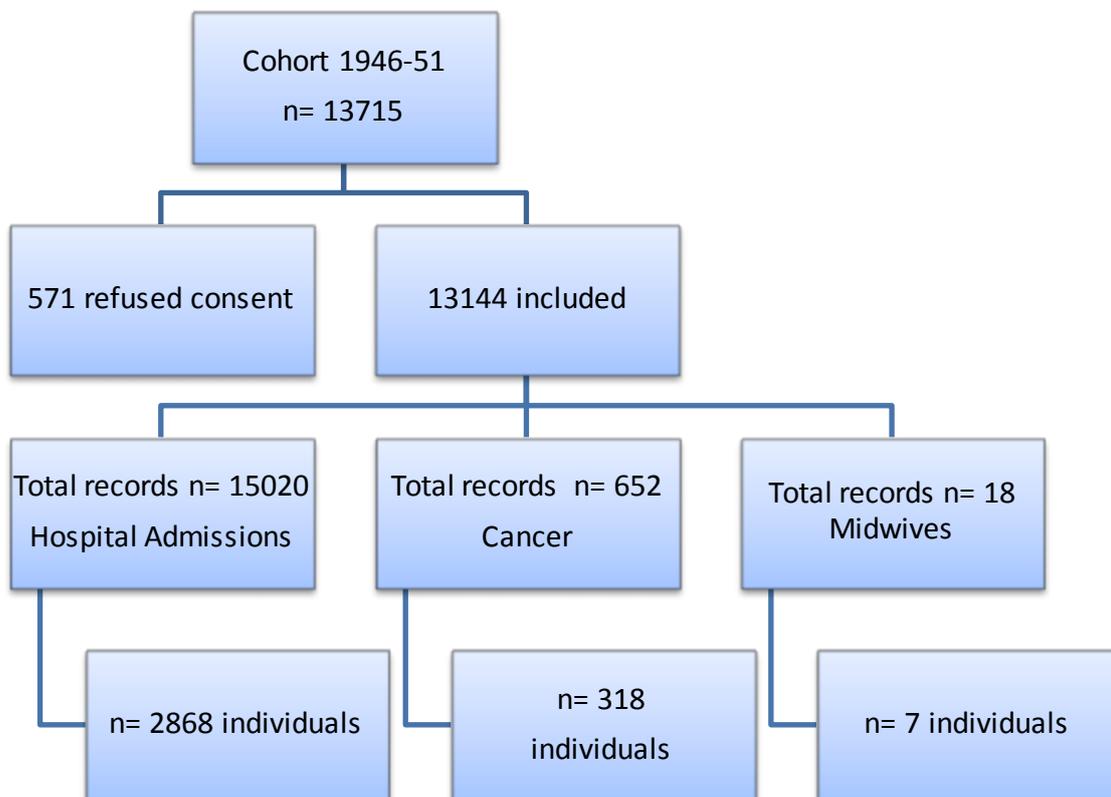


Figure 5 Total number of individuals and records per linked dataset for the 1946-51 cohort in New South Wales

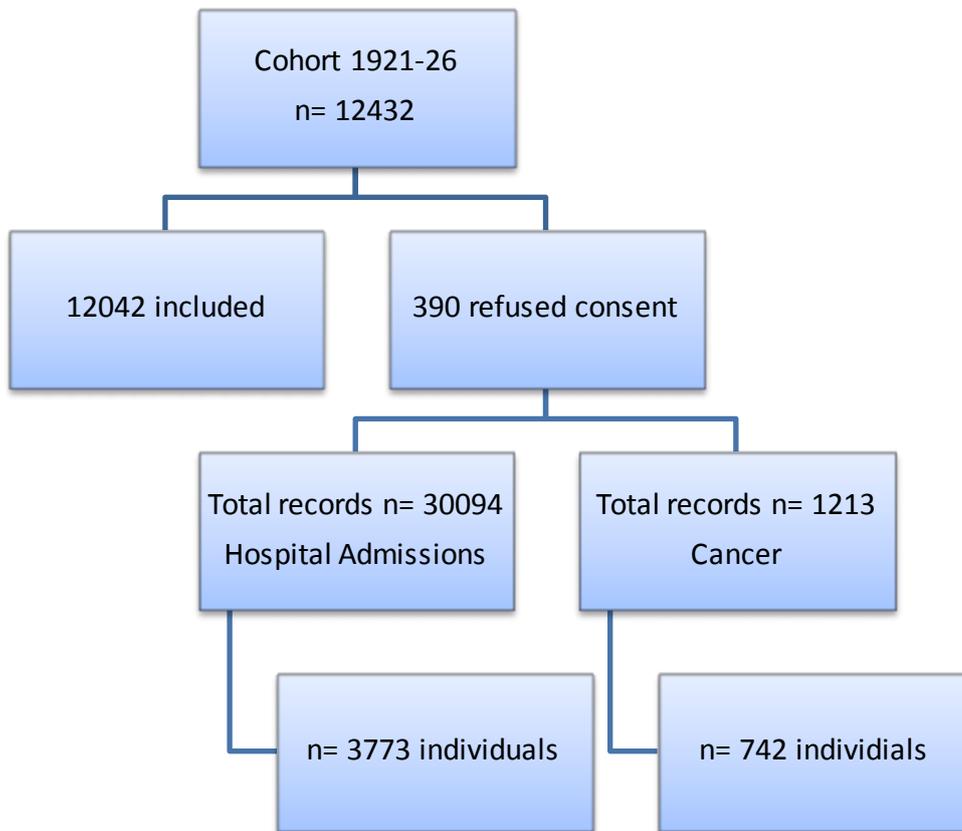


Figure 6 Total number of individuals and records per linked dataset for the 1921-26 cohort in New South Wales

Queensland

Linkages of ALSWH survey data with the **Admitted Patients Data Collection (QHAPDC)**, **Queensland Cancer Registry (QCR)** and **Queensland Perinatal Data Collection (QPDC)** have been approved for the 1973-78, 1946-51 and 1921-26 cohorts. Linkages for the 1989-95 cohort are pending. Identifiers for all participants were provided to the Queensland Health Data Linkage Unit, with the exception of women who had explicitly **refused** consent to data linkages.

QLD QHAPDC- 1993 (linked data from private patients available only from 1 July 2007) to current

- Data collected monthly and finalised on a financial year basis
- It is a compilation of episode-level records, collected from all Queensland hospitals and contains data on all patients separated (an inclusive term meaning discharged, died, transferred or statistically separated) from any hospital permitted to admit patients, including public psychiatric hospitals. Hospitals that are permitted to admit patients must contribute data to QHAPDC for each separation.

QCR- 1982 to current

- Register of all reported cases of cancer in Queensland
- Notification of cancer is a statutory requirement for all public and private hospitals, nursing homes and pathology services. Notifications are received for all persons with cancer separated from public and private hospitals and nursing homes.
- Queensland pathology laboratories provide copies of pathology reports for cancer specimens.
- Data on all persons who die of cancer or cancer patients who die of other diseases are abstracted from the mortality files of the Registrar of Births, Deaths and Marriages and linked to hospital and pathology data.
- All primary cancers with either a malignant, uncertain or in situ behaviour are registered, excluding basal and squamous cell carcinoma of skin. Basal and squamous cell carcinomas of skin are not registered by the Queensland Cancer Registry (nor most other registries) as many are treated in doctor's surgeries using destructive techniques that preclude histological confirmation. Benign brain tumours are registered.
- No staging info

QLD PDC- 1987 to current

- The scope of the Collection includes all live births, and stillbirths of at least 20 weeks gestation and/or at least 400grams in weight.
- a compilation of records collected from all public hospitals, private hospitals, and private midwifery or medical practitioners who deliver babies outside hospitals, for all births occurring in Queensland.

- a basic source of information for research into obstetrics and neonatal care; to provide information on neonatal morbidity and congenital anomalies.
- includes information on antenatal care, the care provided during labour, and the delivery and care provided after birth.

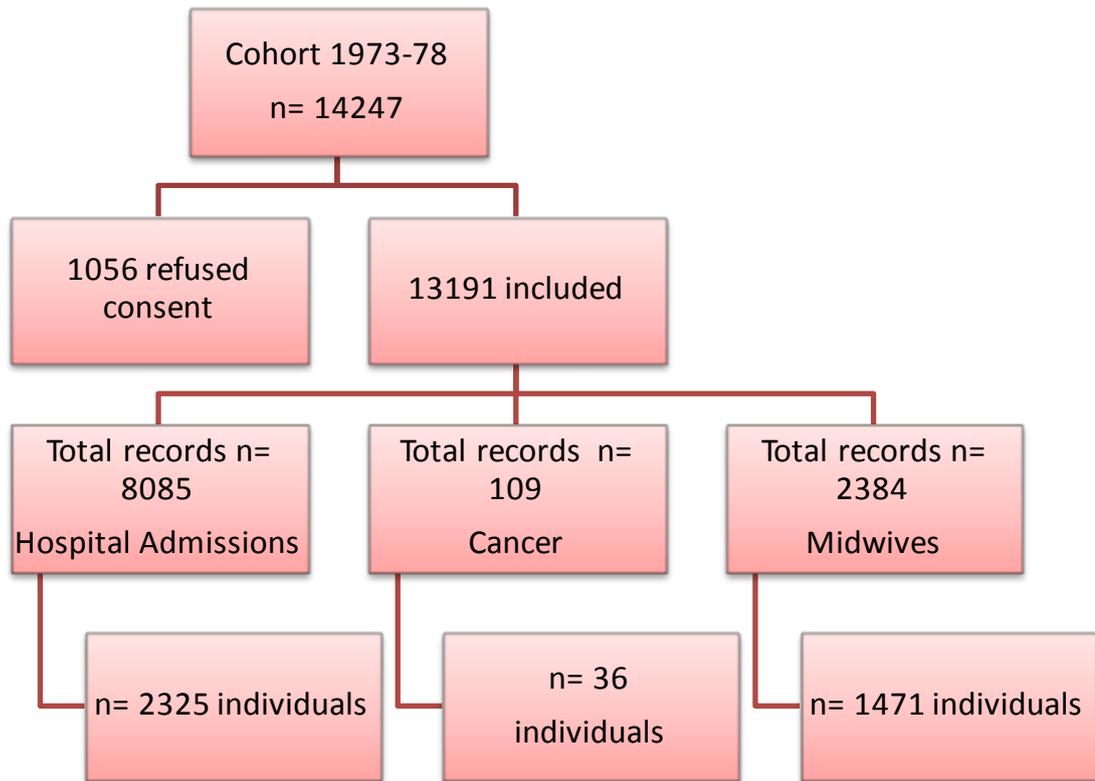


Figure 7 Total number of individuals and records per linked dataset for the 1973-78 cohort in Queensland

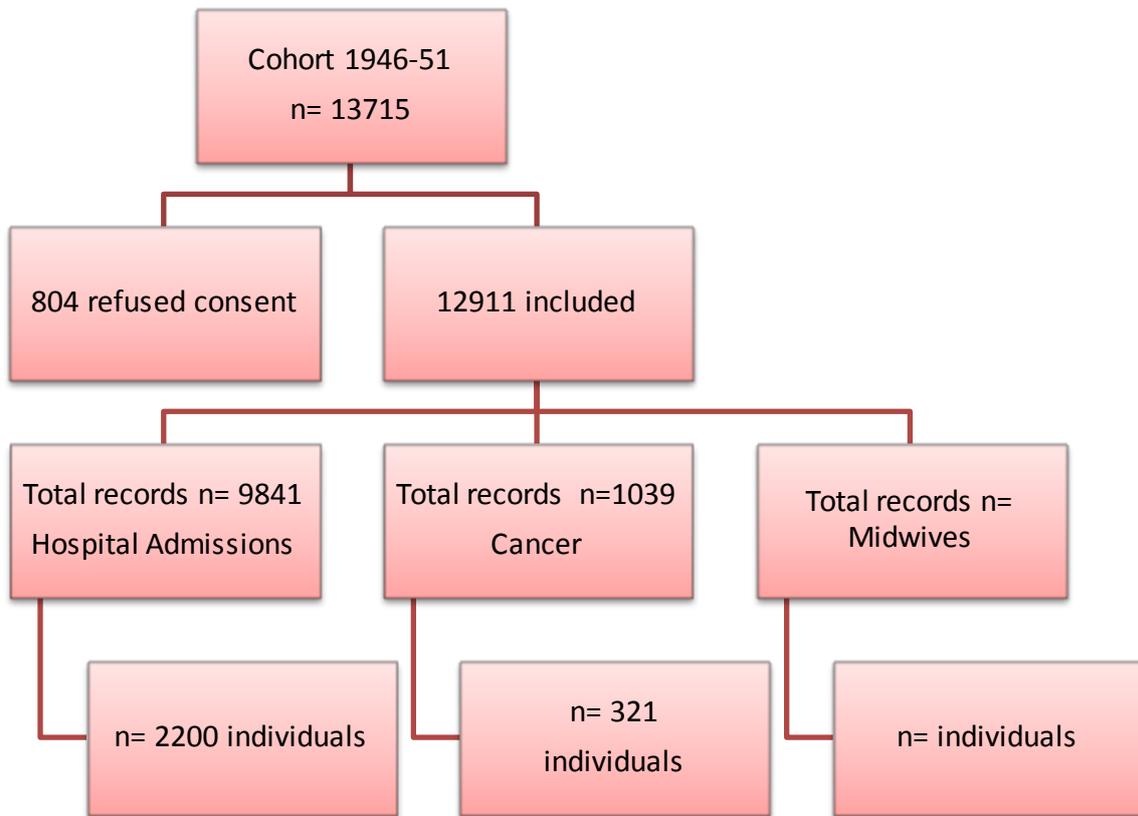


Figure 8 Total number of individuals and records per linked dataset for the 1946-51 cohort in Queensland

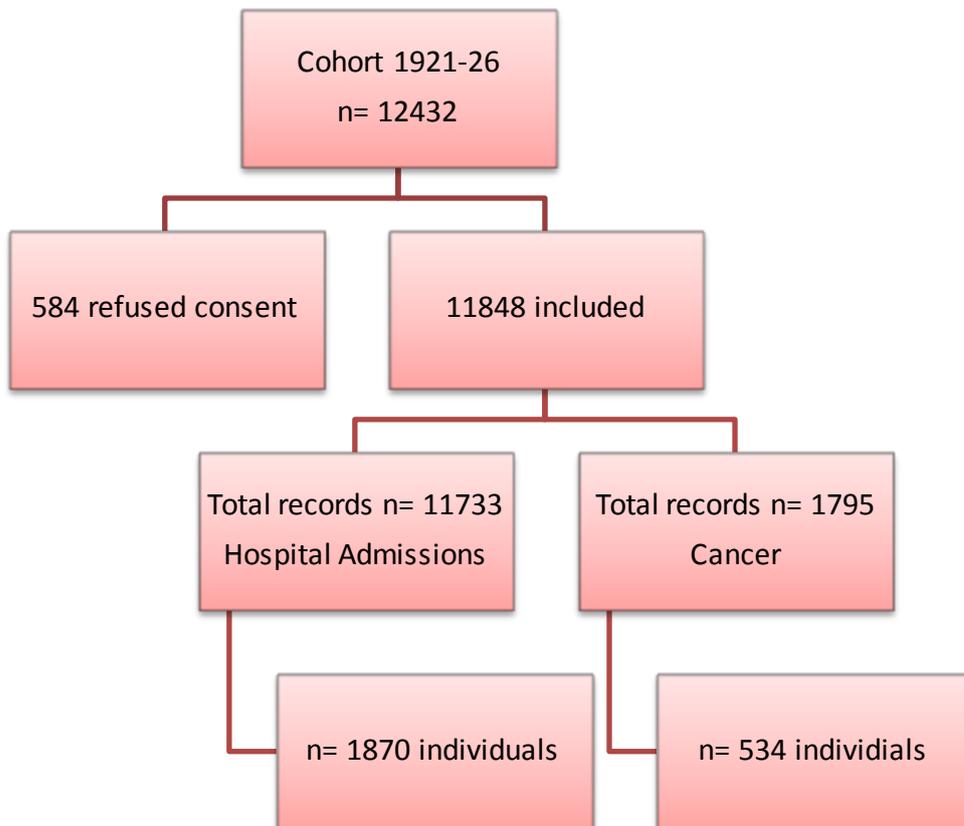


Figure 9 Total number of individuals and records per linked dataset for the 1921-26 cohort in Queensland

South Australia

Linkages of ALSWH survey data with the **Hospital Morbidity Data System (HMDS)** and **Cancer Registry** have been approved for the 1973-78, 1946-51 and 1921-26 cohorts. Linkages for the 1989-95 cohort are pending. Identifiers for all participants **who had provided explicit consent to linkage** were provided to SA-NT DataLink.

SA Inpatient Hospital Separations- 2001 to current

The Integrated South Australian Activity Collection (ISAAC) collects morbidity data on admitted patients from all recognised public and private hospitals in South Australia.

- includes all admitted patient separations (discharges, transfers and deaths) from every South Australian: Public Acute Hospital; Public Psychiatric Hospital; Private Acute Hospital (licensed by SA Health); Private Psychiatric Hospital (licensed by SA Health); and Private Day Surgeries (licensed by Commonwealth). Note that Private separations are currently unavailable for data linkage.

The South Australian Cancer Registry (SACR) - 2000 to current

- Registry is notified by all public and private hospitals and pathology laboratories when a diagnosis of cancer is made.
- SACR provides population-based statistics about cancer incidence, mortality, and case fatality (survival) for the residents of South Australia. The SACR collects a minimum data set for each cancer case, including such elements as place of residence, sex, date of birth, date of diagnosis, cancer site and morphology, means of diagnosis, whether there were multiple primary sites of cancer, race, country of birth, and date, place and cause of death, where applicable.
- Primary sources of information include pathology laboratories, hospitals, radiotherapy departments, the Registrar of Births, Deaths and Marriages (BDM) and other supplementary sources such as clinicians. These notifications are mandated by the SA Cancer Regulations. The information is refined through contact with the primary health-care sector and with other cancer registries, resulting in near 100% ascertainment.

[For further information on variables](#)

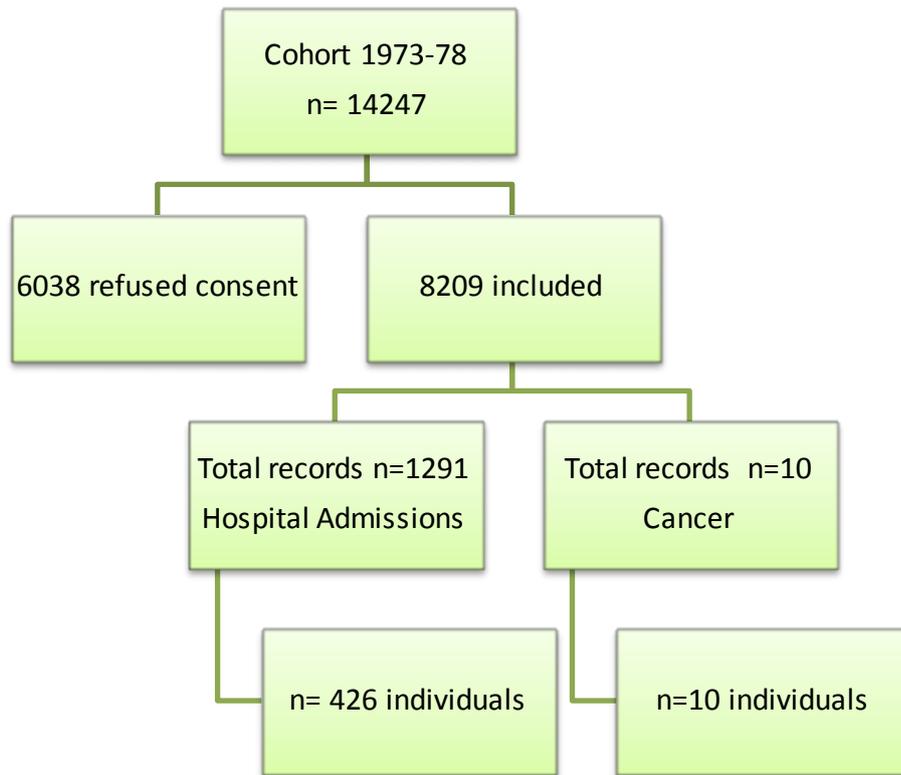


Figure 10 Total number of individuals and records per linked dataset for the 1973-78 cohort in South Australia

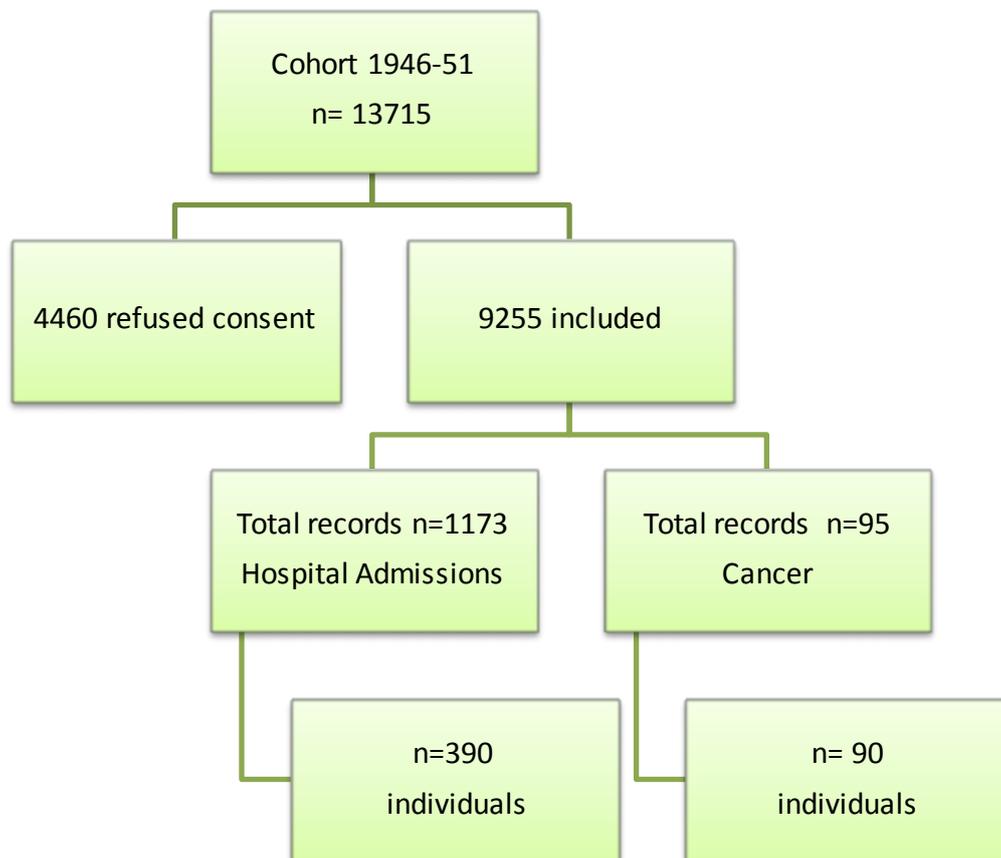


Figure 11 Total number of individuals and records per linked dataset for the 1946-51 cohort in South Australia

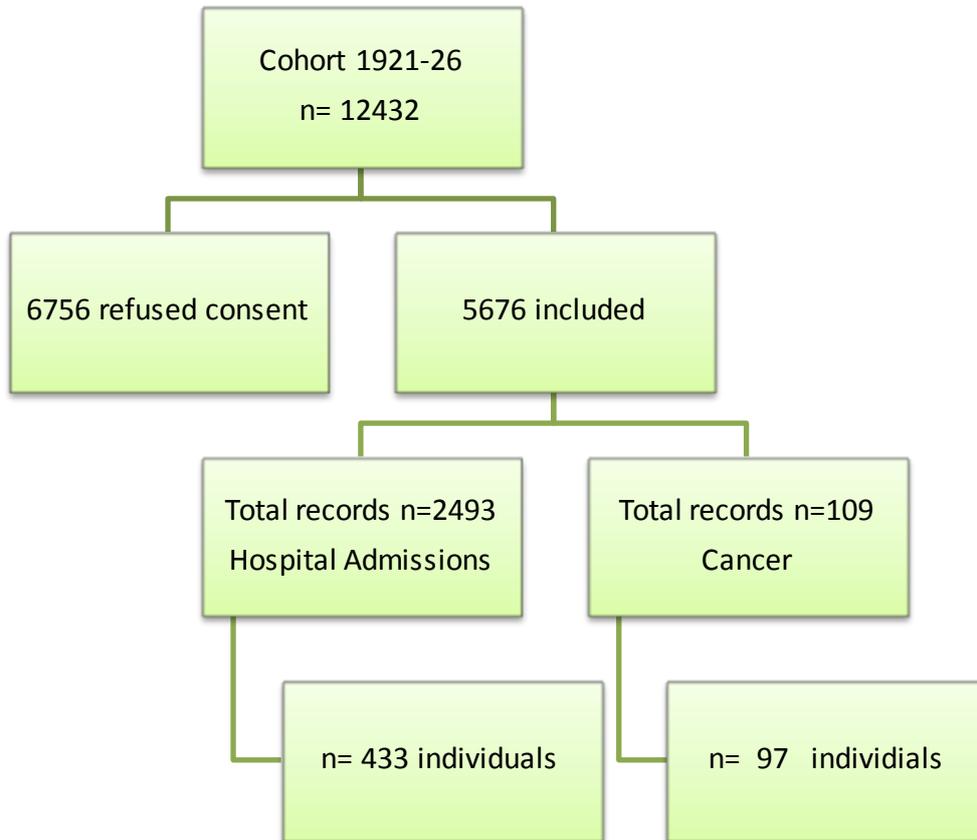


Figure 12 Total number of individuals and records per linked dataset for the 1921-26 cohort in South Australia

Victoria

While linkages of ALSWH survey data to Victorian Hospital data, Midwives collections and Cancer registry have received ethical approval, there are legislative barriers to such linkages in Victoria and the ALSWH has only been able to access data from the Victorian Cancer Registry

Victorian Cancer Registry (VCR) – 1982 to current

The Victorian Cancer Registry (VCR) is a population-based cancer registry aiming to provide comprehensive, accurate and timely information for cancer control. Currently, about 240 hospitals and 30 pathology laboratories notify them of cancer cases. Cancer screening registers are also required to notify us of all cancers.

The VCR records all invasive cancers, in-situ carcinomas, benign tumours and tumours of uncertain behaviour. Basal cell carcinomas or skin cancers aren't recorded. A minimum amount of information is collected for every cancer case to maximise data accuracy. For each cancer case, the following is recorded:

- Demographics (including patient name, address, DOB) and
- Tumour details (including site, morphology, grade, behaviour, date of diagnosis).

The VCR collects information on all cancer diagnosis in Victorian residents. Currently, 75% of cancer notifications are received electronically. All data are processed and stored within the registry database, Precis™ Central. All aspects of data processing involve quality checking to maximise data accuracy.

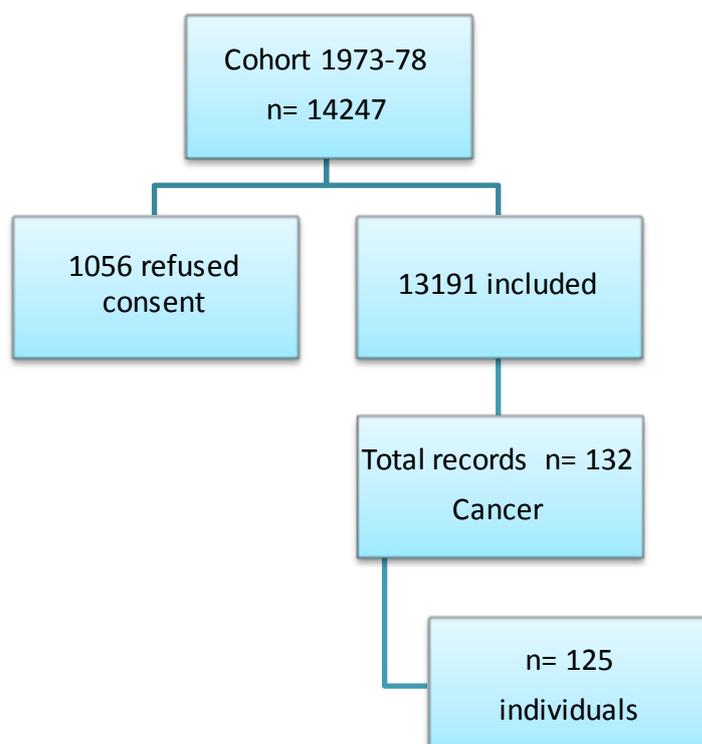


Figure 13 Total number of individuals and records for the 1973-78 cohort in Victoria

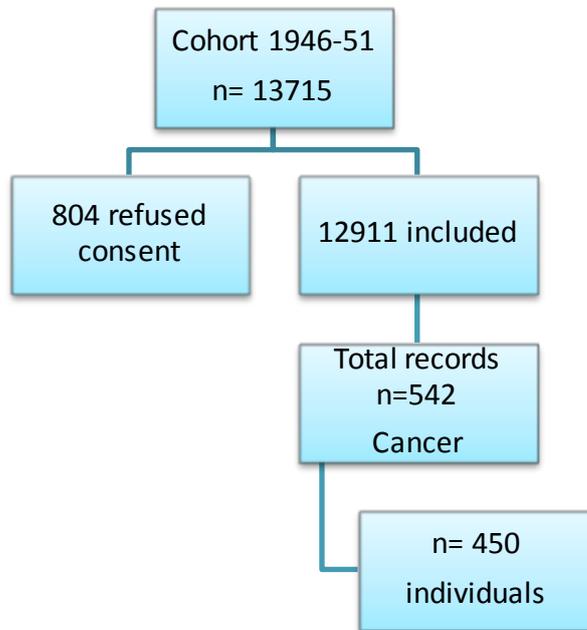


Figure 14 Total number of individuals and records for the 1946-51 cohort in Victoria

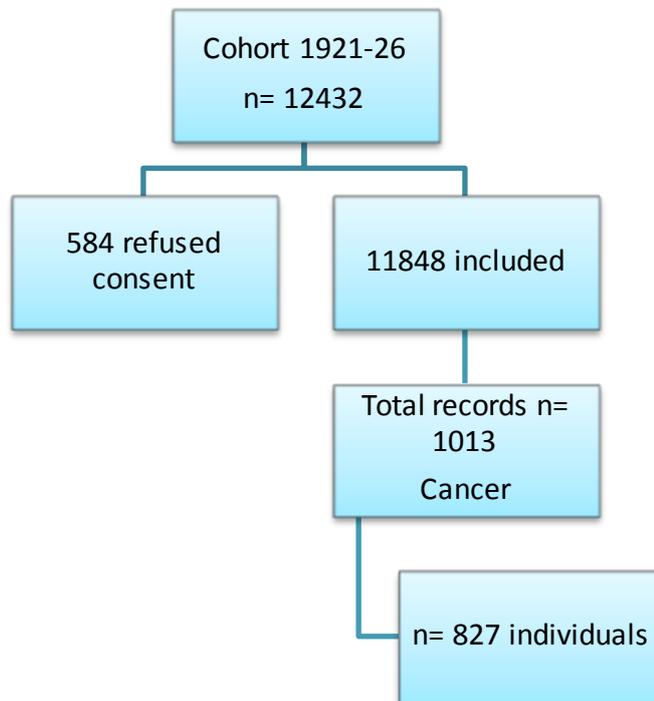


Figure 15 Total number of individuals and records for the 1921-26 cohort in Victoria