

Data Quality Statement

Summary

Name	Prostate Cancer Outcomes Registry New South Wales (PCOR-NSW)
Description	PCOR-NSW is a prospective clinical cancer registry that captures diagnosis, treatment, prostate cancer specific quality of life and mortality data for men diagnosed with prostate cancer in NSW.
Date last updated	15 February 2024
Organisation	Cancer Institute NSW (Institute)
Sponsor	Chief Cancer Officer and Chief Executive Officer, Cancer Institute NSW
Steward(s)	Data Quality Officer, Cancer Institute NSW Coordinator, PCOR-NSW, Cancer Institute NSW
Custodian	Lisa McCallum, Manager, Data Governance, Cancer Institute NSW
Legislation and authority	Cancer Institute (NSW) Act 2003 Public Health Act 2010
Data reference period	01 January 2015 to most recent data available
Scheduled data release	Annually
Data update frequency	Annually
Data type	Unit record data
Privacy and confidentiality	Data will be used and disclosed in accordance with the Privacy and Personal Information Protection Act (PPIPA), Health Records and Information Privacy Act (HRIPA) and Ministry of Health Policies.
Data asset version number	Version 1.0
Data Quality Statement version number	Version 1.0
Identifiers for linkage	<ul style="list-style-type: none">• EncryptedPK___PatientID (encryption key)• Surname• First Given Name• Second Given Name• Sex• Street Number and Name• Suburb or Town• Postcode• State or Region• Date of birth• Date of diagnosis• Date of death

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	<ul style="list-style-type: none">• Country of birth• Facility Code
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Abstract

The PCOR-NSW is a prospective cancer registry that captures diagnosis, treatment, prostate cancer specific quality of life and mortality data for men diagnosed with prostate cancer in NSW held by Cancer Institute NSW. The PCOR-NSW is the NSW arm of the Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR ANZ) (<https://prostatecancerregistry.org>); a bi-national initiative funded by the Movember Foundation, supported in kind by Cancer Institute NSW and managed by Monash University to work towards establishing a population-based clinical registry to improve the health outcomes for men living with prostate cancer in Australia and New Zealand. Cancer Institute NSW has established the PCOR-NSW in partnership with the NSW Agency for Clinical Innovation. The PCOR-NSW is governed by the PCOR-NSW Steering Committee.

The PCOR-NSW has been in operation since February 2016 and includes data on eligible men diagnosed with prostate cancer from 1 January 2015 onwards to the present. Participation rates of clinicians, facilities, and patients have continued to increase since 2015. PCOR-NSW is not currently a population-based dataset.

PCOR-ANZ produce annual reports based on the latest most complete information available in the PCOR-ANZ, in which data collected by the PCOR-NSW is included. Comparisons are made at a bi-national level with other participating jurisdictions across Australia and New Zealand.

Key Metrics

This section covers the key areas of relevance, accuracy, and coherence.

Relevance

Scope and coverage	
Data collection purpose	To improve health outcomes for men living with prostate cancer in Australia and work towards establishing a population-based clinical registry. PCOR-NSW is the NSW arm of the Prostate Cancer Outcomes Registry Australia and New Zealand (PCOR-ANZ); a national initiative funded by the Movember® Foundation.
Target population	Prostate cancer data is collected for all men aged 18 or older, whose treating clinician or hospital is participating in the registry, irrespective of the state or country in which they reside. A prostate cancer diagnosis must be pathologically confirmed for the patient to be included on the registry.
Data collection period	01 January 2015 to most recent data available
Exceptions to data collection period	None.
Geographic Detail	

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Level of geographical data	Patient postcode, state, country of residence, country of birth
Geographical coverage	Data is collected from facilities in NSW, but participants may reside in any state or country. Where a NSW resident has sought treatment in another PCOR-ANZ jurisdiction, that data is obtained from the relevant jurisdiction and entered in the NSW database.
Standards used	<ul style="list-style-type: none"> • Cancers are coded according to the International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3) • TNM overall grouping is assigned based on the AJCC 8th edition guidelines • NCCN Clinical Practice Guidelines in Oncology • Cancer of the Prostate Risk Assessment (CAPRA)
Aboriginality data	Aboriginal status is taken from the NSW Cancer Registry. If Aboriginal status is missing from the NSW Cancer Registry the question is asked directly during follow up.
Typical use and analyses	<p>The PCOR-NSW can be used to:</p> <ul style="list-style-type: none"> • Assess and determine patterns of care for men diagnosed and treated for prostate cancer in NSW • Identify, examine and reduce factors associated with variations in treatments and outcomes for men with prostate cancer • Compare compliance reporting with best practice-based guidelines for the treatment of prostate cancer • Identify factors that predict favourable and unfavourable treatment outcomes, particularly in relation to major adverse effects • Provide information to patients about the risks and benefits of specific approaches to prostate cancer treatment • Support research into prostate cancer at a population level
Other cautions	None

Accuracy

Data collection methods	<p>Data for the PCOR-NSW are sourced from the NSW Cancer Registry, medical records in participating hospitals, rooms of participating clinicians and directly from participating men. Quality of life information is collected directly from participants at 12 months and where possible, also at baseline and 24 months. A small proportion of true baseline information is captured by participating clinicians and is transferred to the PCOR-NSW. Most baseline data is collected retrospectively at the 12-month time point. Only three baseline questions are asked, and participants are asked to rate their overall urinary, bowel and sexual function prior to their diagnosis of prostate cancer. Where a participant has their diagnosis or treatment</p>
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	across jurisdictions, information is shared across participating jurisdictions in Australia and New Zealand.
Coverage	Overall coverage of PCOR-NSW was 38% of men diagnosed in NSW between 2015 and 2019. Coverage has increased over time and was 55% in 2019. Associations between survival and most risk factors measured in PCOR-NSW participants were generally similar to associations measured in the NSW population of men diagnosed with prostate cancer.
Error types	<p>As the PCOR-NSW is a prospective registry and relies on data from the NSW Cancer Registry to identify eligible men, there are likely to be cases that are missed due to incomplete notifications, i.e., hospital notification only without corresponding pathology report. This is due to the variation in frequency by which notifications are received into the NSW Cancer Registry and the time coding for any given incidence year is completed. There is currently a two-year difference between the PCOR-NSW and the NSW Cancer Registry. The NSW Cancer Registry team actively follow-up missing notifications for the incidence year they are working on.</p> <p>The PCOR-NSW attempts to ensure accuracy and completeness of information collected through the sources of data available to it. Namely, the NSW Cancer Registry, medical records at participating hospitals, information available in the rooms of participating specialists and from participating men. Where access is restricted as has often been the case during the recent pandemic, quality and completeness has been impacted. Information may sometimes vary or be discrepant between data sources.</p> <p>Survey questions from the Expanded Prostate Cancer Index Composite ask about potentially sensitive topics such as urinary, bowel, and sexual function. Participants may not answer truthfully if they are embarrassed or uncomfortable with the personal nature of the questions. Participants who do not have a current partner or whose partner may be deceased tend to leave the sexual function questions blank or report poor function but state that it is no problem as it's not important to them.</p>
Steps to minimise processing errors	<p>Data quality audits are undertaken by PCOR-ANZ annually.</p> <p>Issues that may impact data accuracy are human error and system-related or database issues. Protocols, policies and quality control processes are in place and regularly reviewed to minimise these errors.</p>
Data revision or correction	Data is audited periodically by Monash University. If discrepancies or missing information is found, PCOR-NSW will review and correct as needed.

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Coherence/Change Notes

Changes to data items/data collection	Collection of Magnetic Resonance Imaging (MRI) and Prostate Imaging-Reporting and Data System (PI-RADS) information were added in 2019.
Comparison across data items	Data is collected by data collectors who have undergone the same standardised training. This data set can be compared across multiple data items within the PCOR-NSW collection and is consistently collected throughout Australia and New Zealand.
Comparison with other products available	PCOR-NSW can be linked and compared to the NSW Cancer Registry (https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/request-unlinked-unit-record-data-for-research/nsw-cancer-registry). PCOR-NSW includes everyone diagnosed or treated in NSW where their diagnosing or treating clinician and/or hospital are also participating, regardless of patient location of residence whereas the NSW Cancer Registry only includes patients that reside in NSW.

User Notes

This section covers the key areas of interpretability and accessibility.

Interpretability

Data sources	<p>There are four components to the PCOR-NSW:</p> <ol style="list-style-type: none"> 1. Incidence data – demographics and diagnosis information for people with prostate cancer is obtained from the NSW Cancer Registry 2. Clinical data – information about people treated for prostate cancer in NSW and their treatments are obtained from the NSW Cancer Registry and participating doctors and facilities 3. Mortality data – the PCOR-NSW obtains death notifications (which includes date of death and cause of death) from the NSW Registry of Births, Deaths and Marriages. This is sourced from the Australian Bureau of Statistics, as received through the NSW Cancer Registry 4. Health-related quality of life data – participants in the PCOR-NSW can choose to complete the Expanded Prostate Cancer Index Composite: Short Form 26 (EPIC-26) questionnaire which examines the impact their prostate cancer diagnosis/treatment has had upon their urinary, bowel, sexual and hormonal health. This data is sourced directly from participants.
Elements	Refer to the data asset data dictionary for the complete list of data elements.
Elements with interpretation issues	The definition of “active” treatment may differ between PCOR-ANZ and clinicians which may lead to differences in the timing of the collection of patient reported measures from EPIC-26.

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	<p>Clinician definitions may consider treatment as primary but PCOR-ANZ definitions may consider treatment salvage.</p> <p>All participants are asked to provide the date on which they have completed the survey, EPIC-26 (Variable name: EPIC Completion Date). If this field is left blank, the date the survey was received is used. This date may be either the day the survey was received in the mail or opened and scanned. This date is relevant as people who utilise it might look at the date EPIC-26 completed in comparison to date of diagnosis and subsequent treatments.</p>
Completeness	A completeness report for this data will be available on our website in the future.
Additional data context	None.
Error correction	<p>The data supplied undergoes regular data quality review and correction cycles at regular intervals.</p> <p>Existing records are changed if:</p> <ul style="list-style-type: none"> • new, more precise information about the diagnosis or person becomes available • any typographical errors are discovered by routine data checking procedures • if it is discovered that the initial diagnosis of cancer was incorrect (for example, the tumour was in fact benign). These records are retracted and removed from the database.
Data delays	<ul style="list-style-type: none"> • PCOR-NSW relies on the NSW Cancer Registry to identify patients so if information is missing from the NSW Cancer Registry it will likely also be missing from PCOR-NSW. • Hospitals, cancer treatment providers and pathology labs may sometimes have delays in submission of data to the NSW Cancer Registry. • Delays in reporting occurred from some facilities impacted by the COVID-19 pandemic since 2020. Some smaller facilities do not have the infrastructure to allow for remote access and COVID-19 restrictions have caused delays in data access.

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Accessibility

Relevant publications and reports	<p>Publications and reports that have used PCOR-NSW data:</p> <ul style="list-style-type: none"> • https://prostatecancerregistry.org/publications/newsletters-annual-reports/ • https://www.cancer.nsw.gov.au/cancer-control-2019/cancer-treatment-and-services/focus-project-nsw-prostate-clinical-cancer-registry
How to access data	<p>Unlinked data requests can be made at: https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-on-request</p> <p>PCOR-NSW is included in the Enduring Cancer Data Linkage (CanDLe). Further information about access to CanDLe is available at: https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-on-request/candle-program</p> <p>PCOR-NSW is prelinked in The Centre for Health Record Linkage (CHeReL) For more information see https://www.cherel.org.au/about-us</p> <p>Data for linkage to NSW Health datasets is available at https://www.cherel.org.au/datasets</p> <p>General enquiries about PCOR-NSW data can be made to CINSW-DARenquiries@health.nsw.gov.au</p>

For further information regarding this data quality statement please contact CINSW-DARenquiries@health.nsw.gov.au

References

Australian Bureau of Statistics, ABS Data Quality Statement Checklist, Australian Bureau of Statistics, Canberra, accessed 11 May 2022,
<https://www.abs.gov.au/websitedbs/D3310114.nsf/home/ABS+Data+Quality+Statement+Checklist>.