

Cancer Institute NSW

Prostate Cancer Outcomes Registry – NSW (PCOR-NSW) Data Access Policy

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Document Title:	Prostate Cancer Outcomes Registry – NSW (PCOR-NSW) Data Access Policy			
Summary:	This policy provides a framework by which data can be obtained from the PCOR-NSW. This policy includes the criteria, conditions, procedures to be followed and where relevant the fees for such access.			
Date of Issue:	22-Mar-24	Next Review Date:	24-Mar-25	
Status:	Active	Review Cycle:	Annual	
Contact Officer:	Coordinator, Prostate Cancer Outcomes Registry - NSW			
Applies To:	All individuals, clinicians, researchers, departments, and organisations wishing to access PCOR-NSW data.			
References:	Cancer Institute NSW Data Governance Policy (Ref: E10/13359) Health Records and Information Privacy Act PCOR-NSW Data Quality Statement			
Version and Change History	Version	Who	Date	What
	0.0	S Teuss and N Grayson	01/04/2016	Drafted document
	0.1	S Teuss	26/4/2016	Revised document
	0.2	S Teuss and S Edwards	27/4/2016	Edits
	0.3	S Edwards and N Grayson	18/07/2016	Revised document
	0.4	Steering Committee and S Edwards	02/08/2016	Revisions to “Conditions of Disclosure”, additional links and minor wording changes
	1.1	S Teuss	27/09/2017	Addition of contributing clinicians, hospitals and men obtaining access to their own case level data
	1.2	S Teuss	09/11/2017	Revision of participant access to data to include only tabulated data to hospitals and case level data to treating clinicians that relate to information they have provided the PCCR Addition of condition regarding use of data provided to participating hospitals and clinicians
	1.3	S Teuss	19/03/2018	Updated PCCR Data Custodian
	1.4	S Teuss	06/03/2024	Changes include: <ul style="list-style-type: none"> updated name from NSW Prostate Clinical Cancer

				Registry (PCCR) to Prostate Cancer Outcomes Registry – NSW (PCOR-NSW) <ul style="list-style-type: none"> updated web links
	1.5	S Teuss	22/03/2024	<ul style="list-style-type: none"> Incorporated and accepted suggested changes by S Edwards and L McCallum Removed reference to the collection of baseline and 24 quality of life information under scope as this is no longer collected Added purpose of policy to align with new policy template Reordered headings and sections to better align with new policy template Renamed consenting men to participating individuals under “Approvals” section Populated glossary as per new policy template Incorporated gender-neutral language by removing the references to men and replacing them with participants, registrants, and individuals. Ensured consistency of acronyms
Reviewer(s)	Version	Who	Date	What
		S Edwards	20/03/2024	<ul style="list-style-type: none"> updated Data Custodian simplified data availability and removed order of data to be released as no longer relevant reworded notification to the PCOR-ANZ Steering Committee to be annually reported inclusion of reference to Data Quality Statement

		L McCallum	20/03/2024	<ul style="list-style-type: none"> • removal of reference to tabulated under data format section • inclusion of reference to Data Quality Statement
Approvals	Version	Who	Date	Record
Cancer Institute NSW	1.0	Privacy, Security, and Right to Information Working Group	31/08/2016	Email – E16/29103
NSW PCCR Steering Committee	1.0	PCCR Steering Committee	22/09/2016	Minutes – E16/32556
Cancer Institute NSW	1.0	David Currow, Chief Cancer Officer	19/10/2016	E16/32799
NSW Population and Health Services Research Ethics Committee	1.3	Ethics Committee	05/07/2018	E18/24193
Data Governance Manager	1.5	L McCallum	25/03/2024	Noted against E24/05441

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1. Introduction

1.1. Overview

The Prostate Cancer Outcomes Registry - NSW (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 to establish a clinical registry to improve the health outcomes for people living with prostate cancer in Australia and New Zealand.

The Cancer Institute NSW (Institute) has established PCOR-NSW in partnership with the NSW Agency for Clinical Innovation. The PCOR-NSW is governed by the PCOR-NSW Steering Committee.

The data collected helps to guide best clinical practices and processes and improve quality of patient care and outcomes in NSW.

The Institute recognises the benefits from and encourages the use of PCOR-NSW data for the public good. This Data Access Policy has been developed to support making PCOR-NSW data available.

1.2. Purpose

The purpose of this policy is to provide a framework by which data can be obtained from PCOR-NSW.

1.3. Scope

The PCOR-NSW captures diagnosis, treatment, quality of life and mortality data for men diagnosed with prostate cancer in NSW from 1 January 2015.

Data for PCOR-NSW are sourced from the NSW Cancer Registry (NSWCR), medical records in participating hospitals, and from the rooms of participating clinicians. Quality of life information is collected directly from men at 12 months after their treatment or diagnosis of prostate cancer. PCOR-NSW Data Dictionary and Quality Statement will be available on the Cancer Institute NSW website: <https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-on-request/request-unit-record-data-for-research/nsw-prostate-clinical-cancer-registry>

1.4 Data Custodian

The Data Custodian (DC) for PCOR-NSW is the Data Governance Manager, Cancer Institute NSW

1.5 Approvals

PCOR-NSW has ethical approval to operate and collect data from participating individuals or for those for whom a waiver of consent has been approved, from the NSW Population and Health Services Research Ethics Committee (PHSREC) [HREC/15/CIPHS/7] [CINSW 2015/02/578]. Approval is in place until 13 March 2025.

Site specific approvals for participating hospitals in the public sector have been obtained from Local Health District (LHD) Research Governance Offices and agreements and/or contracts with participating clinicians and organisations in the private sector have been made. These approvals expire as per PHSREC approval.

2 Data Access Process

2.1 Application and Approval

To access PCOR-NSW data, requestors are required to complete a data request form which will be referred to the data custodian for approval. Information regarding data access including a copy of the request form is available on the Institute's website

<https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-on-request/request-unit-record-data-for-research>

Depending on the nature of the request, approval from the PHSREC may also be required. The requirements for submission to PHSREC can be found at

<https://www.cancer.nsw.gov.au/research-and-data/nsw-population-health-services-research-ethics-com>

Where applicable, authorisation to disclose the data will be provided by the Ministry of Health (in the case of individually identifiable data) or the Chief Cancer Officer (CCO), following DC approval and, if applicable, PHSREC approval. This will be arranged by the Institute.

The PCOR-NSW Steering Committee will be notified of requests on an annual basis.

2.2 Access to Data by Participating Individuals, Clinicians and Hospitals

If data from a particular hospital or hospitals is required, approval from the respective LHD may also be necessary.

Participating hospitals may have access to tabulated data. Data release must be authorised by a nominated senior consultant (Head of Department from which data is being requested) within each hospital.

Participating clinicians may have access to their own case level data. Case level data refers to data provided by that participating clinician to PCOR-NSW. Information obtained from other sources will not be provided.

Access to data about an individual participant may be provided to the individual to whom it relates, provided that the requestor is able to provide sufficient proof of identification.

2.3 Data Availability

Data will be made available for research in a phased approach based on the quality and completeness of data in PCOR-NSW. Please refer to the Data Quality Statement (DQS) on the Institute's website: <https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-on-request/request-unit-record-data-for-research/nsw-prostate-clinical-cancer-registry>

2.4 Data Formats

PCOR-NSW data will be made available in Excel or Word format. De-identified individual record data from the PCOR-NSW will be made available in CSV format, unless otherwise agreed.

2.5 Fees

Depending on the nature and complexity of the request a fee may be applied in line with the Institute’s data access charging policy. Fees will be quoted and communicated to the requestor prior to any work being undertaken.

2.6 Support and Advice

For initial queries about the availability and quality of PCOR-NSW data, the PCOR-NSW Coordinator should be contacted at cinsw-pcornsw@health.nsw.gov.au

3 Terms and Conditions

PCOR-NSW contains data from the NSWCR. Data in the NSWCR was obtained in connection with the execution of the Public Health Act 2010. Therefore, disclosure of PCOR-NSW data must be in line with the NSW Ministry of Health’s policy directive PD2015_037 Data collections–Disclosure of unit record data for research or management of health services. The conditions for disclosure can be found at http://www0.health.nsw.gov.au/policies/pd/2015/pdf/PD2015_037.pdf.

Additional conditions for disclosure of PCOR-NSW data include:

- “Data sourced in this publication has been obtained from the Prostate Cancer Outcomes Registry - NSW which is funded by Movember and Cancer Institute NSW, and supported by Monash University and the NSW Agency for Clinical Innovation”

Data provided to participating clinicians and sites must be used for internal purposes only.

Any use of the data for external purposes must be declared and where applicable obtain approval as indicated in section 2.

3.1 Conflicts of Interest

Members of the PCOR-NSW Steering Committee will apply for access to the data in the same way as other requestor. All applications for data will be submitted via the Institute’s Data Access process. Any conflicts of interest should be declared during the application process.

4 Glossary

Term	Definition
Institute	Cancer Institute NSW
CCO	Chief Cancer Officer
DC	Data Custodian
DQS	Data Quality Statement
LHD	Local Health District
NSWCR	NSW Cancer Registry
PHSREC	NSW Population and Health Services Research Ethics Committee
PCOR-NSW	Prostate Cancer Outcomes Registry - NSW
PCOR-ANZ	Prostate Cancer Outcomes – Australia and New Zealand