

# NSW Prostate Clinical Cancer Registry Data Access Policy

Version 1.3 | 19 March 2018

<b>Document Title:</b>	<i>NSW Prostate Clinical Cancer Data Access Policy</i>			
<b>Summary:</b>	<i>This policy provides a framework by which data can be obtained from the NSW Prostate Clinical Cancer Registry. This policy includes the criteria, conditions, procedures to be followed and where relevant the fees for such access.</i>			
<b>Date of Issue:</b>	<i>23/09/2016</i>			
<b>Status:</b>	<i>Final</i>			
<b>Contact Officer:</b>	<i>NSW PCCR Coordinator</i>			
<b>Applies To:</b>	<i>All individuals, clinicians, researchers, departments and organisations wishing to access PCCR data.</i>			
<b>References:</b>	<i>Cancer Institute NSW Data Governance Policy (HPRM reference E10/13359[v1]) Health Records and Information Privacy Act</i>			
<b>Version and Change History</b>	<b>Version</b>	<b>Who</b>	<b>Date</b>	<b>What</b>
	0.0	<i>S Teuss and N Grayson</i>	<i>1/4/2016</i>	<i>Drafted document</i>
	0.1	<i>S Teuss</i>	<i>26/4/2016</i>	<i>Revised document</i>
	0.2	<i>S Teuss and S Edwards</i>	<i>27/4/2016</i>	<i>Edits</i>
	0.3	<i>S Edwards and N Grayson</i>	<i>18/07/2016</i>	<i>Revised document</i>
	1.0	<i>Steering Committee and S Edwards</i>	<i>02/08/2016</i>	<i>Revisions to "Conditions of Disclosure", additional links and minor wording changes</i>
	1.1	<i>S Teuss</i>	<i>27/09/2017</i>	<i>Addition of contributing clinicians, hospitals and men obtaining access to their own case level data</i>
	1.2	<i>S Teuss</i>	<i>09/11/2017</i>	<i>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</i>

				<i>hospitals and clinicians</i>
	1.3	<i>S Teuss</i>	<i>19/03/2018</i>	<i>Updated PCCR Data Custodian</i>
<b>Approvals</b>	<b>Version</b>	<b>Who</b>	<b>Date</b>	<b>Record</b>
Cancer Institute NSW	1.0	<i>Privacy, Security, and Right to Information Working Group</i>	31/08/2016	<i>Email – E16/29103</i>
NSW PCCR Steering Committee	1.0	<i>PCCR Steering Committee Members</i>	22/09/2016	<i>Minutes – E16/32556</i>
Cancer Institute NSW	1.0	<i>David Currow, Chief Executive Officer and Chief Cancer Officer</i>	19/10/2016	<i>E16/32799</i>
NSW PCCR Steering Committee	1.2	<i>PCCR Steering Committee Members</i>	11/10/2017	<i>E17/40163</i>
NSW Population and Health Services Research Ethics Committee	1.3	<i>Ethics Committee Members</i>	27/04/2018	<i>E18/18484</i>
Cancer Institute NSW	1.3	<i>David Currow, Chief Executive Officer and Chief Cancer Officer</i>	26/05/2018	<i>E18/09652</i>

## 1. Introduction

The NSW Prostate Clinical Cancer Registry (PCCR) 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 population-based clinical registry to improve the health outcomes for men living with prostate cancer in Australia and New Zealand.

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

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

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

## 2. Overview

### Scope

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

Data for the PCCR are sourced from the NSW Cancer Registry, patient's medical records in participating hospitals, and from the rooms of participating clinicians. Quality of life information is collected directly from men shortly after diagnosis (baseline), 12 and 24 months after their treatment or diagnosis of prostate cancer.

The PCCR Data Dictionary will be available on the Cancer Institute NSW website <http://nsw-prostate-registry.cancerinstitute.org.au/>

### Data Custodian

The data custodian for the PCCR is the Data Governance Manager, Cancer Institute NSW.

### Approvals

The PCCR has ethical approval to, operate and collect data from consenting men 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 2020 and will be extended in line with funding arrangements.

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.

## 3. Data Access Process

### Application and approval

To access the PCCR 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 Cancer Institute NSW website [www.cancerinstitute.org.au](http://www.cancerinstitute.org.au).

Depending on the nature of the request, approval from the NSW Population and Health Services Research Ethics Committee may also be required. The requirements for submission to PHSREC can be found at <https://www.cancerinstitute.org.au/data-research/research-ethics/submissions>

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, following data custodian approval and, if applicable, ethics committee approval. This will be arranged by the Cancer Institute NSW.

The PCCR Steering Committee will be notified of requests.

### **Access to Data by Participating Men, Clinicians and Hospitals**

If data from a particular hospital or hospitals is required, approval from the respective Local Health District 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 the PCCR. 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.

### **Data availability**

Data will be made available in a phased approach and in the following order:

PCCR Statistics - aggregated data including; age (grouped), year of diagnosis, method of diagnosis

1. PCCR Treatment - aggregated data including; age (grouped), year of diagnosis, method of diagnosis, treatment type e.g. surgery, radiotherapy, chemotherapy
2. PCCR Patient Reported Outcomes Measures – De-identified responses to EPIC-26 questionnaire

Additional modules will be released in the future depending on the volume of data available

### **Data formats**

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

## **4. Terms and Conditions**

The PCCR 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 PCCR 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](http://www0.health.nsw.gov.au/policies/pd/2015/pdf/PD2015_037.pdf).

Additional conditions for disclosure of PCCR data include:

- “Data sourced in this publication has been obtained from the NSW Prostate Clinical Cancer Registry 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 3.

## **5. Fees**

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

## **6. Conflicts of interest**

Members of the NSW Prostate Clinical Cancer Registry 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 Cancer Institute NSW’s Data Access process (Section 3). Any conflicts of interest should be declared during the application process.

## **7. Support and advice**

For initial queries about the availability and quality of PCCR data, the PCCR Coordinator should be contacted at [nswpccr@cancerinstitute.org.au](mailto:nswpccr@cancerinstitute.org.au).