

NSW Prostate Clinical Cancer Registry Data Access Policy

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Document Title:	<i>NSW Prostate Clinical Cancer Data Access Policy</i>			
Summary:	<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>			
Date of Issue:	<i>23/09/2016</i>			
Status:	<i>Final</i>			
Contact Officer:	<i>NSW PCCR Coordinator</i>			
Applies To:	<i>All individuals, clinicians, researchers, departments and organisations wishing to access PCCR data.</i>			
References:	<i>Cancer Institute NSW Data Governance Policy (HPRM reference E10/13359[v1]) Health Records and Information Privacy Act</i>			
Version and Change History	Version	Who	Date	What
	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>
	0.4	<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>
Approvals	Version	Who	Date	Record
Cancer Institute NSW	1.0	<i>Privacy, Security, and Right to Information Working Group</i>	<i>31/08/2016</i>	<i>Email - E16/29103</i>
NSW PCCR Steering Committee	1.0	<i>PCCR Steering Committee</i>	<i>22/09/2016</i>	<i>Minutes - E16/32556</i>
Cancer Institute NSW	1.0	<i>David Currow, Chief Cancer Officer</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 Manager, Registries and Data Collection, 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 May 2020.

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.

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>

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.

Data availability

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

1. PCCR Statistics - aggregated data including; age (grouped), year of diagnosis, method of diagnosis
2. PCCR Treatment - aggregated data including; age (grouped), year of diagnosis, method of diagnosis, treatment type e.g. surgery, radiotherapy, chemotherapy
3. PCCR Patient Reported Outcomes Measures – Deidentified 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.

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”

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.