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Prostate Cancer Outcomes Registry-NSW Data Dictionary (PCOR-ANZ)

Version 1.0 | 14 February 2024

This dictionary has the following structure:

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Table 1 Demographics

ID	Variable Name	Variable Description	Variable Format / Values
1	Country of birth	Country of birth of participant based on the Standard Australian Classification of Countries https://www.abs.gov.au/statistics/classifications/standard-australian-classification-countries-sacc/latest-release)	FORMAT: NNNN VALUES:
2	Aboriginality	The Aboriginality code for the participant. Permission is required from the **Aboriginal Health and Medical Research Council** when publishing reports utilising this data element.	FORMAT: N VALUES: 1=Aboriginal but not Torres Strait Islander origin 2=Torres Strait Islander but not Aboriginal origin 3=Both Aboriginal and Torres Strait Islander origin 4=Neither Aboriginal or Torres Strait Islander origin 5=Aboriginal and/or Torres Strait Islander (unspecified) 6=Not stated/Inadequately described '-1=Data collected prior to database
3	Age at diagnosis	Calculated age at diagnosis of prostate cancer. Calculated by (date of birth - date of diagnosis)/365.25	FORMAT: NN.NN VALUES:
4	Vital status	Latest known vital status at the time of data extraction	FORMAT: N VALUES: 0=Alive 1=Dead 5=Dead (not confirmed) 9=Not known
5	Date of death	The full date of death of the participant	FORMAT: YYYY-MM-DD VALUES: Valid date
6	Participant status	Status of the participant at the time of data extraction	FORMAT: N VALUES: 1=Yes 2=Waiver of consent for TURP (unaware) 3=Waiver of consent for Death 4=Pending 5=Data collection only
7	Postcode	Current residential postcode of participant at the time of data extraction.	FORMAT: NNNN VALUES: Valid postcode

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ID	Variable Name	Variable Description	Variable Format / Values
8	State or region	Current residential state/territory of participant at time of data extraction.	FORMAT: N VALUES: 1=NSW 2=VIC 3=QLD 4=SA 5=WA 6=TAS 7=NT 8=ACT 9=Unknown 10=Overseas resident 11=Northland 12=Auckland 13=Waikato 14=Bay of Plenty 15=Gisborne 16=Hawke's Bay 17=Taranaki 18=Wairarapa 19=Wellington 20=Nelson-Marlborough 21=Manawatu 22=South Canterbury 23=West Coast 24=Canterbury 25=Otago 26=Southland
9	Country	Usual country of residence based on the Standard Australian Classification of Countries https://www.abs.gov.au/statistics/classifications/standard-australian-classification-countries-sacc/latest-release	FORMAT: NNNN VALUES:
10	No fixed address	Noting if the participant has no fixed address as confirmed by the participant.	FORMAT: String VALUES: False=Address known (not checked) True=Address not known
11	Institution ID	The facility from which the participant's prostate cancer notification was received.	FORMAT: String VALUES:

Table 2 Diagnosis

ID	Variable Name	Variable Description	Variable Format / Values
1	Date of diagnosis	The date of the procedure that provided a diagnosis of prostate cancer	FORMAT: YYYY-MM-DD VALUES: Valid date

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ID	Variable Name	Variable Description	Variable Format / Values
2	Method of diagnosis	This is the first method that provided a definitive diagnosis of prostate cancer.	FORMAT: N VALUES: 1=TRUS 2=TURP 3=TURBT 4=Transperineal biopsy 5=Clinical Investigation (eg Bone scan, CT, MRI) 6=Histology of metastatic site - (bone biopsy Lymph node biopsy) 7=Prostatectomy (simple, diagnostic) 8=Other 9=Unknown 10=Cystoprostatectomy 11=Biopsy taken but approach not stated/ inadequately specified
3	Years with prostate cancer at death	Calculated years of participant living with prostate cancer. Calculated by (date of death - date of diagnosis)/365.25	FORMAT: NN.NN VALUES: 01 - 85+
4	Sector	Identifying the facility where the diagnosis occurred as private or public	FORMAT: N VALUES: 1=Public 2=Private 3=Unknown
5	Initial testing (presentation prior to diagnosis)	Symptomatic refers to symptoms such as nocturia, based on urologist or GP or both. Asymptomatic refers to rising PSA with no symptoms.	FORMAT: N VALUES: 1=Asymptomatic (detected through routine screening) 2=Symptomatic (presented with symptoms) 3=Unknown '-1=Data collected before online database
6	Diagnosis PSA status	If the participant's PSA was collected at diagnosis	FORMAT: N VALUES: -2=Not Taken -1=Not Stated 1=Taken 2=PSA taken >180 days before diagnosis date
7	Diagnosis PSA Level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N-NNNNN.NN VALUES:
8	Diagnosis PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date

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ID	Variable Name	Variable Description	Variable Format / Values
9	Clinical T stage status	Diagnosis clinical T (cT) stage status	FORMAT: N VALUES: 0=DRE not taken (cT not done) 1=DRE taken and cT provided and clearly documented in medical record 2=DRE taken but cT not documented clearly in medical record (awaiting information from clinician) 3=DRE taken but cT initially not documented clearly in medical record but subsequently provide by clinician 4=DRE taken and cT assigned by data collector 5=DRE refused by patient 6=DRE not taken (cT derived)
10	Histology Type 1	Histology is coded as the International Classification of Diseases for Oncology (ICD-0-3) morphology codes. The morphological codes comprise a five-digit number (NNNNN) which describes the cell type (or histology) NNNN of the tumour, together with the behaviour (malignant or benign).	FORMAT: NNNNN VALUES: ICD-0-3 morphology codes. See Appendix 1.
11	Histology type 2	Histology is coded as the International Classification of Diseases for Oncology (ICD-0-3) morphology codes. The morphological codes comprise of a five-digit number (NNNNN) which describes the cell type (or histology) of the tumour, together with the behaviour (malignant or benign).	FORMAT: NNNNN VALUES: ICD-0-3 morphology codes. See Appendix 1.
12	Total number of cores	The total number of cores or biopsy samples taken during a TRUS or transperineal biopsy.	FORMAT: N VALUES: Total number of cores -2=No pathology report
13	Number of positive cores	Cores refer to the biopsy samples (derived from the needle biopsies) in specimen jars. A specimen jar may contain one or more cores. This data field refers to the number of cores or biopsy samples taken that have a Gleason score during a TRUS or transperineal biopsy.	FORMAT: N VALUES: Number of positive cores -2=No pathology report

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ID	Variable Name	Variable Description	Variable Format / Values
14	Percentage of positive cores	A derived field. The percentage of positive cores is calculated by Number of Positive Cores / Total Number of Cores * 100	FORMAT: N VALUES:
15	Total number of cassettes	The total number of specimens or jars in a sample.	FORMAT: N VALUES: Total number of cassettes (specimens) -2=No pathology report
16	Number of positive cassettes	The number of positive specimens or jars in the sample, where at least one core within the specimen or jar, has a Gleason score.	FORMAT: N VALUES: Total number of cassettes (specimens) -2=No pathology report
17	Percentage of positive cassettes	A derived field. The percentage of positive cassettes is calculated by Number of Positive cassettes / Total Number of cassettes * 100	FORMAT: N VALUES:
18	Primary Gleason score	The Primary Gleason score is a number that refers to the most dominant or common pattern of cancer found in the prostate specimen.	FORMAT: N VALUES: 1-5 -1=Not stated -2=No pathology report -3=Insufficient sample
19	Secondary Gleason score	The Secondary Gleason score is a number that refers to the second most common or dominant pattern, or may be the highest grade found within the specimen, depending on the pathology guidelines used.	FORMAT: N VALUES: 1-5 -1=Not stated -2=No pathology report -3=Insufficient sample
21	Total Gleason score	The Gleason sum is a measure of the aggressiveness of prostate cancer and is the sum of two numbers (the primary and secondary grades).	FORMAT: N VALUES: 1-6=Low/very low 7=Intermediate 8-10=High/very high -1=Not stated -2=No pathology report -3=Insufficient sample
22	Bone scan status	If a bone scan was done to assist in N and M staging	FORMAT: String VALUES: True=Yes False=No
23	Date of bone scan	Date of bone scan at diagnosis	FORMAT: YYYY-MM-DD VALUES: Valid date
24	CT status	If a CT scan was done to assist in N and M staging	FORMAT: String VALUES: True=Yes False=No

ID	Variable Name	Variable Description	Variable Format / Values
25	Date of CT scan	Date of CT scan at diagnosis	FORMAT: YYYY-MM-DD VALUES: Valid date
26	Diagnosis MRI status	If a MRI scan was performed at diagnosis	FORMAT: N VALUES: 0=No 1=Yes 9=Not known
27	MRI Date	Date of MRI scan at time of diagnosis	FORMAT: YYYY-MM-DD VALUES: Valid date
28	PET status	If a PET scan was done to assist in N and M staging	FORMAT: String VALUES: True=Yes False=No
29	PIRADS score	The Prostate Imaging Reporting and Data System (PI-RADS) reports how likely that a suspicious area on an MRI is a clinically significant cancer. The score is taken from the latest MRI before the date of diagnosis.	FORMAT: N VALUES: 1=Very low 2=Low 3=Intermediate (undetermined) 4=High 5=Very High
30	Date of PET scan	Date of PET scan at diagnosis	FORMAT: YYYY-MM-DD VALUES: Valid date
31	Radiology test status	If no scans or radiology tests were done	FORMAT: String VALUES: True=No radiology test done False=No (not checked)
32	Other imaging status	If another scan was performed to assist N & M staging	FORMAT: String VALUES:
33	Imaging unknown	If unknown radiology tests were conducted to assist staging	FORMAT: String VALUES: True=Yes (not known) False=No (known)
34	Lymphovascular invasion	Refers to cancer (tumour) spreading to lymphatic and/or blood vessels	FORMAT: N VALUES: 0=No 1=Yes -1=Not stated -2=No pathology report -3=Data collected prior to database

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ID	Variable Name	Variable Description	Variable Format / Values
35	Perineural invasion	Refers to cancer (tumour) spreading, growing, infiltrating, or invading to a space around a nerve or within a nerve.	FORMAT: N VALUES: 0=No 1=Yes -1=Not stated -2=No pathology report -3=Data collected prior to database
36	Seminal vesicle invasion	Refers to the presence of prostate cancer in the areolar connective tissue around the seminal vesicles and outside the prostate.	FORMAT: N VALUES: 0=No 1=Yes -1=Not stated -2=No pathology report -3=Data collected prior to database
37	Extraprostatic invasion	Refers to the cancer (tumour) extending outside the capsule but NOT into the seminal vesicle.	FORMAT: N VALUES: 0=No 1=Yes -1=not stated -2=no pathology report -3=data collected prior to database
38	T stage	A categorical description ranging from TX to T4, depending on the level of involvement of cancer, felt in the prostate during a digital rectal examination (DRE). This should NOT be confused with the pathological T obtained within pathology reports.	FORMAT: N VALUES: 1=TX (cannot be assessed) 2=T0 3=T1 4=T1a 5=T1b 6=T1c 7=T2 8=T2a 9= T2b 10=T2c 11=T3 12=T3a 13=T3b 14=T4 15=T4a 16=T4b

ID	Variable Name	Variable Description	Variable Format / Values
39	M stage	M stage indicates the absence or presence of distant metastases at the time of diagnosis of the primary cancer. It is part of the AJCC TNM cancer staging system	FORMAT: N VALUES: 1=MX 2=M0 7=M1 3=M1a 4=M1b 5=M1c 6=Inconclusive
40	N stage	N stage score describes the extent of regional lymph node metastases.	FORMAT: N VALUES: 0=N0 1=N1 2=NX (nodes not biopsied) -1=Not stated '-2=No pathology report
41	TNM overall grouping	Generated by the database and are derived from the following data fields: PSA, Gleason score. Patients are placed in Group I-IV accordingly. TNM overall grouping is assigned based on the AJCC 8th edition guidelines.	FORMAT: N VALUES: 1=Stage I 2=Stage IIA 3=Stage IIB 4=Stage III 5=Stage IV 6=Not stated
42	NCCN score	NCCN score is generated by the database and are derived from the following data fields: PSA, Gleason score, TNM and % positive cores. Patients are placed in low, intermediate, high and metastatic categories accordingly.	FORMAT: N VALUES: 1=CL:low risk disease 2=CL:Int risk disease 3=CL:high risk disease 4=LA:very high risk disease 5=LA:metastatic disease '-1=Not classified
43	CAPRA score	CAPRA score is generated by the database and are derived from the following data fields: PSA, Gleason score, TNM and % positive cores. Patients are placed in low, intermediate, high and metastatic categories accordingly.	FORMAT: N VALUES: 0,1=Low risk 3,4,5=Intermediate risk 6,7,8,9,10=High risk '-1=Not stated

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Table 3 Treatments

ID	Variable Name	Variable Description	Variable Format / Values
Treatment - Summary			
1	Accumulative treatment summary	Summary of treatment(s) received by participants	FORMAT: String VALUES:
2	Earliest treatment	The earliest treatment type	FORMAT: String VALUES:
3	Latest treatment	The latest treatment type	FORMAT: String VALUES:
4	Latest primary active treatment date	Latest Treatment Date is the start date of the latest primary active treatment that occurs within 12 months from date of diagnosis. If no primary active treatment has occured, or primary active treatment occurs >12 months after diagnosis date, then Latest treatment date is = date of diagnosis. Active treatment includes Primary Surgery, Radiotherapy, Brachytherapy, Whole-gland ablation and Focal-gland ablation.	FORMAT: DD/MM/YYYY VALUES: Valid date
Treatment - Surgery			
1	Surgery status	If the participant underwent a prostatectomy	FORMAT: N VALUES: 0=No 1=Yes 2=Pending 9=Not known
2	Date of surgery	The date surgery was performed	FORMAT: YYYY-MM-DD VALUES: Valid date
3	Surgical approach	Type of surgery	FORMAT: N VALUES: 3=Robot assisted laparoscopic prostatectomy 4=Open (converted from laparoscopic) 5=Open (converted from robotic) 7=Other prostatectomy 6062=Laser assisted prostatectomy 6065=Open prostatectomy 6069=Laparoscopic prostatectomy -1=Unknown type of prostatectomy

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ID	Variable Name	Variable Description	Variable Format / Values
4	Surgery PSA status	If the participant's PSA was collected prior to surgery	FORMAT: N VALUES: 1=Taken -1=Not Stated '-2=Not Taken
5	Surgery PSA level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N-NNNNN.NN VALUES:
6	Surgery PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date
7	Surgery presence of tumour	If surgery indicated the presence of a tumor.	FORMAT: N VALUES: 0=No 1=Yes 9=Not known -1=Collected prior to new database
8	Surgery extraprostatic invasion	If the cancer (tumour) extended outside the capsule but NOT into the seminal vesicle.	FORMAT: N VALUES: 0=No 1=Yes -1=Not stated -2=No pathology report -3=Data collected prior to database
9	Surgery seminal vesicle invasion	If the prostate cancer invades the muscular wall of the seminal vesicle.	FORMAT: N VALUES: 0=No 1=Yes -1=Not stated -2=No pathology report -3=Data collected prior to database
10	Surgery perineural invasion	If the cancer (tumour) was spreading, growing, infiltrating, or invading to a space around a nerve or within a nerve.	FORMAT: N VALUES: 0=No 1=Yes -1=Not stated -2=No pathology report -3=Data collected prior to database
11	Surgery nerve sparing status	Nerve preservation during surgery to assess any implication on the level of bother from side effects the patient will experience	FORMAT: N VALUES: 1=Non-nerve-sparing 2=Nerve-sparing -1=Unknown -3=Collected prior to DB build

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ID	Variable Name	Variable Description	Variable Format / Values
12	Surgery lymphovascular invasion	If the cancer (tumour) was spreading to blood vessels or lymphatics or lymphovascular space or spaces.	FORMAT: N VALUES: 0=No 1=Vessel not known 2=Artery 3=Vein 4=Lymph 5=Multiple vessel types -1= Not stated -2=No pathology report -3=Data collected prior to database '-4=Non recruiting hospital
13	Surgery histology type	The codes are based on the International Classification of Diseases for Oncology (ICD-0-3) morphology codes. The morphological codes comprise of a five-digit number (NNNNN) which describes the cell type (or histology) of the tumour, together with the behaviour (malignant or benign).	FORMAT: NNNNN VALUES: ICD-0-3 morphology codes. See Appendix 1.
14	Surgery T stage	T stage identifies the extent of the tumour at the primary site. It commonly refers to the tumour size and extent at the time of diagnosis. It is part of the AJCC TNM cancer staging system.	FORMAT: TX VALUES: 1=TX (not assessed) 2=T0 7=T2 8=T2a 9=T2b 10=T2c 11=T3 12=T3a 13=T3b 14=T4 15=T4a 16=T4b -1=Not stated -2=No pathology report
15	Surgery N Stage	N stage indicates the absence or presence of regional lymph node metastases, and the extent of nodal involvement, at the time of diagnosis of the primary cancer. It is part of the AJCC TNM cancer staging system.	FORMAT: N VALUES: -2=No pathology report -1=Not stated 0=N0 1=N1 2=NX (nodes not biopsied)

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ID	Variable Name	Variable Description	Variable Format / Values
16	Surgery primary Gleason score	The Gleason score (primary) is a number that refers to the most dominant or common pattern of cancer found in the prostate specimen.	FORMAT: N VALUES: 1=1 2=2 3=3 4=4 5=5 -1=Not stated -2=No pathology report -3=Insufficient sample
17	Surgery secondary Gleason score	The Gleason score (secondary) is a number that refers to the second most common or dominant pattern or may be the highest grade found within the specimen, depending on the pathology guidelines used.	FORMAT: N VALUES: 1-5 -1=Not stated -2=No pathology report -3=Insufficient sample
18	Surgery total Gleason score	The Gleason sum is a measure of the aggressiveness of prostate cancer and is the sum of two numbers (the primary and secondary grades).	FORMAT: N VALUES: 1-6=Low/very low 7=Intermediate 8-10=High/very high -1=Not stated -2=No pathology report -3=Insufficient sample
19	Pathological margins	The edge or border of the tissue removed in cancer surgery. Present: The margin is positive or involved if the cancer cells are at the edge of the tissue, suggesting that not all of the cancer is removed.	FORMAT: N VALUES: 1=Present 2=Absent 3=Abuts margin 4=Equivocal: pathological (insufficient sample to enable definitive margin) 5=Equivocal: inadequate/unclear documentation on the path report -1=Equivocal: margin not stated -2=No pathology report
20	Margin status focality	Number of places the margin has been crossed in a prostatectomy specimen. If pathological margins are positive, the status of the focality needs to be collected. Focal: If the margin is only crossed once (e.g. left apex)(one foci/tumour) Multi-focal: If the margin is crossed in more than one place (e.g. left apex and right base) (1 foci/tumour)	FORMAT: N VALUES: 1=Focal 2=Multi-focal -1=Unknown -3=Collected prior to DB build

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ID	Variable Name	Variable Description	Variable Format / Values
21	Focal extensive margins	If the margins are reported as 'positive' or 'involved', specify the extent or involvement of the margin. It is either focal (≤ 1 mm) or extensive (> 1 mm).	FORMAT: N VALUES: 1=≤1mm (focal) 2=>1mm (extensive) -1=Not stated/unknown -2=no pathology report
Treatment - Radiotherapy			
1	Radiotherapy status	If the participant underwent radiotherapy treatment	FORMAT: N VALUES: 0=No 1=Yes 2=Pending 9=Not known
2	External beam radiotherapy	Use of external beam radiotherapy	FORMAT: N VALUES: 0=No 1=Yes 9=Not known
3	Unknown radiotherapy	If the radiotherapy type is unknown	FORMAT: N VALUES: 0=No 1=Yes
4	Total dose	Cumulative prescribed dose of EBRT (Gy) administered during the course of treatment for prostate cancer.	FORMAT: NN VALUES:
5	Total dose unknown	If the total dose (Gy) for primary/salvage radiotherapy is unknown	FORMAT: String VALUES: True=Dose Unknown False=Dose Known
6	Number of fractions	The total number of fractions for primary/salvage radiotherapy	FORMAT: NN VALUES:
7	Number of fractions unknown	If the total number of fractions for primary/salvage radiotherapy is unknown	FORMAT: N VALUES: 0=Fractions Known 1=Fractions Unknown
8	Start date of radiotherapy	The start date of radiotherapy.	FORMAT: YYYY-MM-DD VALUES: Valid date
9	Stop date of radiotherapy	The stop date of completed radiotherapy treatment	FORMAT: YYYY-MM-DD VALUES: Valid date
10	Radiotherapy ongoing	If the course of radiotherapy is still in progress or has been completed.	FORMAT: N VALUES: 0=Completed 1=Treatment ongoing
11	Radiotherapy PSA status	If the participant's PSA was collected prior to the start date of radiotherapy	FORMAT: N VALUES: 1=Taken -1=Not Stated '-2=Not Taken
12	Radiotherapy PSA level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N-NNNNN.NN VALUES:

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ID	Variable Name	Variable Description	Variable Format / Values
13	Radiotherapy PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date
Treatment - Surveillance (Active and Watchful Waiting)			
1	Active surveillance status	If the participant underwent active surveillance	FORMAT: N VALUES: 0=No 1=Yes 9=Not known
2	Watchful waiting status	If the participant underwent watchful waiting	FORMAT: N VALUES: 0=No 1=Yes 9=Not known
3	Date of watchful waiting or active surveillance	Date the participant patient made the decision to be monitored by active surveillance/watchful waiting. This date is usually an approximate date and is not a mandatory field.	FORMAT: YYYY-MM-DD VALUES: Valid date
Treatment - ADT			
1	Androgen deprivation therapy status	If the participant underwent androgen deprivation therapy	FORMAT: N VALUES: 0=No 1=Yes 2=Pending 9=Not known
2	ADT type	Type of androgen deprivation therapy.	FORMAT: N VALUES: 1=Chemical 2=Surgical
3	ADT number	The sequence number in the order of androgen deprivation therapies a patient has had (maximum of 8).	FORMAT: N VALUES: 1-8
4	ADT agent	The chemical agent used for androgen deprivation therapy.	FORMAT: NN VALUES: Chemical agents are listed by molecule (brand name). See Appendix 2.
5	Start date of ADT	The start date of androgen deprivation therapy. This can be a date before the Date of Diagnosis or a future date if pending.	FORMAT: YYYY-MM-DD VALUES: Valid date
6	Stop date of ADT	The stop date of androgen deprivation therapy	FORMAT: YYYY-MM-DD VALUES: Valid date
7	Treatment ongoing	ADT ongoing indicates if the ADT is still in progress or has been completed.	FORMAT: N VALUES: 0=Completed 1=Treatment ongoing
8	ADT PSA status	If the participant's PSA was collected prior to the start of ADT	FORMAT: N VALUES: 1=Taken -1=Not Stated '-2=Not Taken

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ID	Variable Name	Variable Description	Variable Format / Values
9	ADT PSA level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N-NNNNN.NN VALUES:
10	ADT PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date
Treatment - TURP			
1	TURP status	If a transurethral resection of the prostate (TURP) was performed	FORMAT: N VALUES: 0=No 1=Yes
2	Date of TURP	Date of the TURP procedure	FORMAT: YYYY-MM-DD VALUES: Valid date
3	TURP presence of tumour	Presence of tumour	FORMAT: N VALUES: 0=No 1=Yes 9=Not Known -1=Collected prior to new database
4	TURP histology type	The codes are based on the International Classification of Diseases for Oncology (ICD-0-3) morphology codes. The morphological codes comprise of a five-digit number (NNNNN) which describes the cell type (or histology) of the tumour, together with the behaviour (malignant or benign).	FORMAT: NNNNN VALUES: ICD-0-3 morphology codes. See Appendix 1.
5	TURP primary Gleason score	The Gleason score (primary) is a number that refers to the most dominant or common pattern of cancer found in the prostate specimen.	FORMAT: N VALUES: 1-5 -1=Not stated -2=No pathology report -3=Insufficient sample
6	TURP secondary Gleason score	The Gleason score (secondary) is a number that refers to the second most common or dominant pattern or may be the highest grade found within the specimen, depending on the pathology guidelines used.	FORMAT: N VALUES: 1-5 -1=Not stated -2=No pathology report -3=Insufficient sample
7	TURP sum Gleason score	The Gleason sum is a measure of the aggressiveness of prostate cancer and is the sum of two numbers (the primary and secondary grades).	FORMAT: N VALUES: 1-6=Low/very low 7=Intermediate 8-10=High/very high -1=Not stated -2=No pathology report -3=Insufficient sample
Treatment - Unknown and Other			

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ID	Variable Name	Variable Description	Variable Format / Values
2	Referred treatment status	If the participant was referred for treatment.	FORMAT: N VALUES: 0=No 1=Yes
3	Other systemic therapies status	If the participant underwent other administered systemic therapies	FORMAT: N VALUES: 0=No 1=Yes 2=Pending 9=Not known
4	Unknown treatment status	If the participant underwent unknown treatment	FORMAT: N VALUES: 0=No 1=Yes
5	Other treatment type	Description of the other treatment type	FORMAT: String VALUES:
6	Start date of other treatment	The start date of other treatment. This must be after date of diagnosis and can only be a future date if pending.	FORMAT: YYYY-MM-DD VALUES: Valid date
7	Stop date of other treatment	The stop date of other treatment	FORMAT: YYYY-MM-DD VALUES: Valid date
8	Other treatment ongoing	Indicates if the treatment is still in progress or has been completed.	FORMAT: N VALUES: 0=Completed 1=Treatment ongoing
9	Start date of other systemic therapies	The start date of other systemic therapies	FORMAT: YYYY-MM-DD VALUES: Valid date
10	Other treatment PSA status	If the participant's PSA was collected prior to the start date of other treatment	FORMAT: N VALUES: 1=Taken -1=Not Stated '-2=Not Taken
11	Other treatment PSA level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N-NNNNN.NN VALUES:
12	Other treatment PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date
Treatment - Brachytherapy			
1	Brachytherapy status	If the participant underwent brachytherapy	FORMAT: N VALUES: 0=No 1=Yes 2=Pending 9=Not known

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ID	Variable Name	Variable Description	Variable Format / Values
2	LDR brachytherapy status	If a low dose rate of brachytherapy was administered	FORMAT: N VALUES: 0=No 1=Yes
3	HDR brachytherapy status	If a high dose rate of brachytherapy was administered	FORMAT: N VALUES: 0=No 1=Yes
4	Unknown type brachytherapy	If the brachytherapy type is unknown	FORMAT: N VALUES: 0=No 1=Yes
5	Date of brachytherapy	The date of brachytherapy. The date must occur after the date of diagnosis and can only be a future date if pending.	FORMAT: YYYY-MM-DD VALUES: Valid date
6	Brachytherapy total dose	Total Dose (Gy) for first course of Brachytherapy	FORMAT: N VALUES:
7	Brachytherapy PSA status	If the participant's PSA was collected prior to the start date of brachytherapy	FORMAT: N VALUES: 1=Taken -1=Not Stated '-2=Not Taken
8	Brachytherapy PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date
9	Brachytherapy PSA level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N-NNNNN.NN VALUES:
Treatment - Focal Gland Ablation			
1	Focal gland ablation therapy	If the participant underwent focal gland ablation therapy	FORMAT: N VALUES: 0=No 1=Yes 2=Pending
2	Date of focal gland ablation therapy	The date of focal-gland ablation therapy. The date must be after date of diagnosis and can only be a future date if 'Pending'	FORMAT: YYYY-MM-DD VALUES: Valid date
3	Focal gland ablation therapy PSA status	If the participant's PSA was collected prior to the start date of focal gland ablation therapy	FORMAT: N VALUES: 1=Taken -1=Not Stated '-2=Not Taken

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ID	Variable Name	Variable Description	Variable Format / Values
4	Focal gland ablation therapy PSA level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N VALUES: N-NNNNN.NN
5	Focal gland ablation therapy PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date
Treatment - Chemotherapy			
1	Chemotherapy status	If the participant underwent chemotherapy	FORMAT: N VALUES: 0=No 1=Yes 9=Not known
2	Start date of chemotherapy	The start date of chemotherapy. The date must be after the date of diagnosis and can only be a future date if 'Pending'	FORMAT: YYYY-MM-DD VALUES: Valid date
3	Stop date of chemotherapy	Thes top date of chemotherapy	FORMAT: YYYY-MM-DD VALUES: Valid date
4	Chemotherapy PSA status	If the participant's PSA was collected prior to start date of chemotherapy	FORMAT: N VALUES: 1=Taken -1=Not Stated '-2=Not Taken
5	Chemotherapy PSA level	PSA level in nanograms of PSA per millilitre of blood (ng/mL)	FORMAT: N-NNNNN.NN VALUES:
6	Chemotherapy PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date

Table 4 Survey Responses

ID	Variable Name	Variable Description	Variable Format / Values
1	EPIC completion date	Date the EPIC-26 survey was completed.	FORMAT: YYYY-MM-DD VALUES: Valid date
2	Lost to follow up status	If the participant was lost to follow up	FORMAT: N VALUES: 0=No 1=Yes

ID	Variable Name	Variable Description	Variable Format / Values
3	Lost to follow up reason	Reason for lost to follow up at 12 month follow up for EPIC-26 survey	FORMAT: N VALUES: 1=Patient deceased 2=Patient unwell 3=Non-English Speaking 4=Unable to Contact 5=Patient not interested in participating (remove date completely from registry) 6=Patient diagnosed earlier than denoted in this notification 7=Late notification from VCR 8=Patient diagnosed in another hospital at an earlier time 9=Waiver for TURP 10=Waiver for death 11=Patient not interested in participating (Consent for data collection only) 12=Dr not recruited at time of follow up 13=Hearing impairment 14=Late notification of TURP awareness 15=Wrong/disconnected number 16=Other (please state) 17=Delayed data collection 18=PROMS not returned 19=Being followed up by another jurisdiction 20=Delayed data collection due to Covid-19
4	Lost to follow up reason other	Description of the reason the participant was lost to follow up if lost to follow up reason is 'Other'	FORMAT: N VALUES:
5	EPIC-26 Question 1 Urine leakage	Over the past 4 weeks, how often have you leaked urine? (Patient-Reported)	FORMAT: N VALUES: 1=More than once a day 2=About once a day 3=More than once a week 4=About once a week 5=Rarely or never
6	EPIC-26 Question 2 Urinary control	Question 2. Which of the following best describes your urinary control during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: 1=No urinary control whatsoever 2=Frequent dribbling 3=Occasional dribbling 4=Total control -1=Participant declines to answer

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ID	Variable Name	Variable Description	Variable Format / Values
7	EPIC-26 Question 3 Urinary diapers	Question 3. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: 1=None 2=1 pad per day 3=2 pads per day 4=3 or more pads per day -1=Participant declines to answer
8	EPIC-26 Question 4A Urinary leakage	Question 4A. How big a problem, if any, has each of the following been for you during the last 4 weeks? Dripping or leaking urine (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem
9	EPIC-26 Question 4B Urinary pain	Question 4B. How big a problem, if any, has each of the following been for you during the last 4 weeks? Pain or burning on urination. (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
10	EPIC-26 Question 4C Urinary bleeding	Question 4C. How big a problem, if any, has each of the following been for you during the last 4 weeks? Bleeding with urination (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
11	EPIC-26 Question 4D Urinary incomplete/weak stream	Question 4D. How big a problem, if any, has each of the following been for you during the last 4 weeks? Weak urine stream or incomplete emptying (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
12	EPIC-26 Question 4E Urinary frequency	Question 4E. How big a problem, if any, has each of the following been for you during the last 4 weeks? Need to urinate frequently during the day (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer

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ID	Variable Name	Variable Description	Variable Format / Values
13	EPIC-26 Question 5 Urinary problem	Question 5. Overall, how big a problem has your urinary function been for you during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
14	EPIC-26 Question 6A Bowel urgency	Question 6A. How big a problem, if any, has each of the following been for you? Urgency to have a bowel movement. (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
15	EPIC-26 Question 6B Bowel frequency	Question 6B. How big a problem, if any, has each of the following been for you? Increased frequency of bowel movements (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
16	EPIC-26 Question 6C Bowel control	Question 6C. How big a problem, if any, has each of the following been for you? Losing control of your stools (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
17	EPIC-26 Question 6D Bowel bleeding	Question 6D. How big a problem, if any, has each of the following been for you? Bloody stools (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
18	EPIC-26 Question 6E Bowel abdominal pain	Question 6E. How big a problem, if any, has each of the following been for you? Abdominal/Pelvic/Rectal pain (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer

ID	Variable Name	Variable Description	Variable Format / Values
19	EPIC-26 Question 7 Bowel problem	Question 7. Overall, how big a problem have your bowel habits been for you during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem -1=Participant declines to answer
20	EPIC-26 Question 8A Erectile ability	Question 8A. How would you rate each of the following during the last 4 weeks? Your ability to have an erection? (Patient-Reported)	FORMAT: N VALUES: 1=Very poor to none 2=Poor 3=Fair 4=Good 5=Very good -1=Participant declines to answer
21	EPIC-26 Question 8B Erectile orgasm	Question 8B. How would you rate each of the following during the last 4 weeks? Your ability to reach orgasm (climax)? (Patient-Reported)	FORMAT: N VALUES: 1=Very poor to none 2=Poor 3=Fair 4=Good 5=Very good -1=Participant declines to answer
22	EPIC-26 Question 9 Erectile quality	Question 9. How would you describe the usual QUALITY of your erections during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: 1=None at all 2=Not firm enough for any sexual activity 3=Firm enough for masturbation and foreplay only 4=Firm enough for intercourse -1=Participant declines to answer
23	EPIC-26 Question 10 Erectile frequency	Question 10. How would you describe the FREQUENCY of your erections during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: 1=I NEVER had an erection when I wanted one 2=I had an erection LESS THAN HALF the time I wanted one 3=I had an erection ABOUT HALF the time I wanted one 4=I had an erection MORE THAN HALF the time I wanted one 5=I had an erection WHENEVER I wanted one -1=Participant declines to answer
24	EPIC-26 Question 11 Sexual functionality	Question 11. Overall, how would you rate your ability to function sexually during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: 1=Very poor to none 2=Poor 3=Fair 4=Good 5=Very good -1=Participant declines to answer

ID	Variable Name	Variable Description	Variable Format / Values
25	EPIC-26 Question 12 Sexual problem	Question 12. Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks? (Patient-Reported)	FORMAT: N VALUES: -1=Participant declines to answer 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem
26	EPIC-26 Question 13A Hot flushes	Question 13A. How big a problem during the last 4 weeks, if any, has each of the following been for you? Hot flushes (Patient-Reported)	FORMAT: N VALUES: -1=Participant declines to answer 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem
27	EPIC-26 Question 13B Breast problem	Question 13B. How big a problem during the last 4 weeks, if any, has each of the following been for you? Breast tenderness/enlargement (Patient-Reported)	FORMAT: N VALUES: -1=Participant declines to answer 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem
28	EPIC-26 Question 13C Depression	Question 13C. How big a problem during the last 4 weeks, if any, has each of the following been for you? Feeling depressed (Patient-Reported)	FORMAT: N VALUES: -1=Participant declines to answer 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem
29	EPIC-26 Question 13D Lack of energy	Question 13D. How big a problem during the last 4 weeks, if any, has each of the following been for you? Lack of energy (Patient-Reported)	FORMAT: N VALUES: -1=Participant declines to answer 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem
30	EPIC-26 Question 13E Weight changes	Question 13E. How big a problem during the last 4 weeks, if any, has each of the following been for you? Change in body weight (Patient-Reported)	FORMAT: N VALUES: -1=Participant declines to answer 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem

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ID	Variable Name	Variable Description	Variable Format / Values
31	LIBIDO Question 1 Sexual interest	Question 1: During the last 4 weeks, to what extent were you interested in sex? (Patient-Reported)	FORMAT: N VALUES: 0=Not at all 1=A little 2=Quite a bit 3=Very much -1=Participant declines to answer -3=Collected prior to DB build
32	LIBIDO Question 2 Use of erectile aids	Question 2: Have you used any medications or devices to aid or improve erections? (Patient-Reported)	FORMAT: N VALUES: 0=No 1=Yes -1=Participant declines to answer -3=Collected prior to DB build
33	LIBIDO Question 3A Erectile tablets	Question 3A: For each of the following medicines or devices, please indicate whether or not you have tried or currently use it to improve your erections: Viagra or another pill (Patient-Reported)	FORMAT: N VALUES: 0=Have not tried it 1=Tried it but was not helpful 2= It helped but I am not using it now 3=It helped and I use it sometimes 4=It helped and I use it always -1=Participant declines to answer -3=Collected prior to DB build
34	LIBIDO Question 3B Erectile MUSE suppository	Question 3B: For each of the following medicines or devices, please indicate whether or not you have tried or currently use it to improve your erections: Muse (intra--urethral alprostadil suppository) (Patient-Reported)	FORMAT: N VALUES: 0=Have not tried it 1=Tried it but was not helpful 2=It helped but I am not using it now 3=It helped and I use it sometimes 4 It helped and I use it always -1=Participant declines to answer -3= Collected prior to DB build
35	LIBIDO Question 3C Erectile injectionables	Question 3C: For each of the following medicines or devices, please indicate whether or not you have tried or currently use it to improve your erections: Penile injection therapy (such as caverject) (Patient-Reported)	FORMAT: N VALUES: 0=Have not tried it 1=Tried it but was not helpful 2=It helped but I am not using it now 3=It helped and I use it sometimes 4 It helped and I use it always -1=Participant declines to answer -3=Collected prior to DB build
36	LIBIDO Question 3D Erectilke vacuum devices	For each of the following medicines or devices, please indicate whether or not you have tried or currently use it to improve your erections: Vacuum erection device (such as erect--aid) (Patient-Reported)	FORMAT: N VALUES: 0=Have not tried it 1=Tried it but was not helpful 2=It helped but I am not using it now 3=It helped and I use it sometimes 4-It helped and I use it always -1=Participant declines to answer -3=Collected prior to DB build

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ID	Variable Name	Variable Description	Variable Format / Values
37	LIBIDO Question 3E Erectile other medication/device	Question 3E: For each of the following medicines or devices, please indicate whether or not you have tried or currently use it to improve your erections: Other medication/device (Patient-Reported)	FORMAT: N VALUES: 0=Have not tried it 1=Tried it but was not helpful 2=It helped but I am not using it now 3=It helped and I use it sometimes 4=It helped and I use it always -1=Participant declines to answer -3=Collected prior to DB build

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Appendix 1 - Residential/state/territory codes

1=NSW

2=VIC

3=QLD

4=SA

5=WA

6=TAS

7=NT

8=ACT

9=Unknown

10=Overseas resident

11=Northland

12=Auckland

13=Waikato

14=Bay of Plenty

15=Gisborne

16=Hawke's Bay

17=Taranaki

18=Wairarapa

19=Wellington

20=Nelson-Marlborough

21=Manawatu

22=South Canterbury

23=West Coast

24=Canterbury

25=Otago

26=Southland81403=Adenocarcinoma

Appendix 2 - ICD-0-3 morphology codes

84803=Mucinous (colloid)

84903=Signet ring-like cell

85003=Ductal adenocarcinoma

81203=Urothelial carcinoma

85603=Adenosquamous carcinoma

80703=Squamous cell carcinoma

81473=Basal cell carcinoma

85743=Adenocarcinoma with neuroendocrine differentiation

82403=Well differentiated neuroendocrine tumour

80413=Small-cell neuroendocrine carcinoma

85723=Sarcomatoid

85002=Intraductal carcinoma

99=Other

100=Unknown

Appendix 3 - Chemical agents by molecule (brand name) codes

-1=Unknown

1=Abiraterone (Zytiga)

2=Bicalutamide (Cosudex)

3=Buserelin Acetate (Superfact)

4=Cyproterone Acetate (Androcur)

5=Degarelix (Firmagon)

6=Enzalutamide (Xtandi)
7=Estramustine (Emcyt)
8=Flutamide
9=Histrelin (Vantas, Supprelin LA)
10=Goserelin (Zoladex)
11=Ketoconazole
12=Leuprolide (Lupron Depot, Lupron Depot-Ped, Viadur, Eligard, Lucrin)
13=Nilutamide (Nilandron, Anandron)
14=Triptorelin Embonate (Diphereline)
15=Triptorelin Pamoate (Trelstar)
16=Other
17=Apalutamide (Erleada, ARN-509)
18=Triptorelin Acetate
19=Relugolix (RVT-601, Relumina)
20=Darolutamide (ODM-201, Nubeqa)

Appendix 4 - Reason lost to follow up codes

1=Patient deceased
2=Patient unwell
3=Non-English Speaking
4=Unable to Contact
5=Patient not interested in participating (remove date completely from registry)
6=Patient diagnosed earlier than denoted in this notification
7=Late notification from VCR
8=Patient diagnosed in another hospital at an earlier time
9=Waiver for TURP
10=Waiver for death
11=Patient not interested in participating (Consent for data collection only)
12=Dr not recruited at time of follow up
13=Hearing impairment
14=Late notification of TURP awareness
15=Wrong/disconnected number
16=Other (please state)
17=Delayed data collection
18=PROMS not returned
19=Being followed up by another jurisdiction
20=Delayed data collection due to Covid-19