

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

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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 <a href="https://www.abs.gov.au/statistics/classifications/standard-australian-classification-countries-sacc/latest-release">https://www.abs.gov.au/statistics/classifications/standard-australian-classification-countries-sacc/latest-release</a> )	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



ID	Variable Name	Variable Description	Variable Format / Values
8	State or region	Current residential state/territory of	FORMAT: N
		participant at time of data	VALUES:
		extraction.	1=NSW
		OXCI GOLIOTII	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	Haud country of residence based on	FORMAT: NNNN
9	Country	Usual country of residence based on the Standard Australian	VALUES:
		Classification of Countries	VALUES.
		https://www.abs.gov.au/statistics/classifications/standard-australian-	
		classification-countries-sacc/latest-	
10	No fixed	release Noting if the participant has no fixed	EODMAT, String
10	address	address as confirmed by the	FORMAT: String VALUES:
	auuress	participant.	False=Address known (not checked)
		participant.	True=Address not known
			True-Address Hot KHOWH
11	Institution ID	The facility from which the	FORMAT: String
''	ottation ib	participant's prostate cancer	VALUES:
		notification was received.	7,12020.

#### Table 2 Diagnosis

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



ID	Variable Name	Variable Description	Variable Format / Values
2	Method of	This is the first method that provided	FORMAT: N
	diagnosis	a definitive diagnosis of prostate	VALUES:
		cancer.	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	Calculated years of participant living	FORMAT: NN.NN
	prostate cancer	with prostate cancer. Calculated by	VALUES:
	at death	(date of death - date of	01 - 85+
		diagnosis)/365.25	
4	Sector	Identifying the facility where the	FORMAT: N
		diagnosis occurred as private or	VALUES:
		public	1=Public
			2=Private
			3=Unknown
5	Initial testing	Symptomatic refers to symptoms	FORMAT: N
	(presentation	such as nocturia, based on urologist	VALUES:
	prior to	or GP or both. Asymptomatic refers	1=Asymptomatic (detected through
	diagnosis)	to rising PSA with no symptoms.	routine screening)
			2=Symptomatic (presented with
			symptoms)
			3=Unknown
			'-1=Data collected before online
			database
6	Diagnosis PSA	If the participant's PSA was	FORMAT: N
	status	collected at diagnosis	VALUES:
			-2=Not Taken
			-1=Not Stated
			1=Taken
			2=PSA taken >180 days before
			diagnosis date
7	Diagnosis PSA	PSA level in nanograms of PSA per	FORMAT: N-NNNNN.NN
	Level	millilitre of blood (ng/mL)	VALUES:
8	Diagnosis PSA	Date the PSA level was collected	FORMAT: YYYY-MM-DD
	date		VALUES:
			Valid date



ID	Variable Name	Variable Description	Variable Format / Values
9	Clinical T stage	Diagnosis clinical T (cT) stage status	FORMAT: N
	status		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	Histology is coded as the	FORMAT: NNNNN
	1	International Classification of	VALUES:
		Diseases for Oncology (ICD-0-3)	ICD-0-3 morphology codes. See
		morphology codes. The	Appendix 1.
		morphological codes comprise a	
		five-digit number (NNNN) which	
		describes the cell type (or histology)	
		NNNN of the tumour, together with	
11	Histology type	the behaviour (malignant or benign).  Histology is coded as the	FORMAT: NNNNN
''	2	International Classification of	VALUES:
	_	Diseases for Oncology (ICD-0-3)	ICD-0-3 morphology codes. See
		morphology codes. The	Appendix 1.
		morphological codes comprise of a	Appendix II
		five-digit number (NNNNN) which	
		describes the cell type (or histology)	
		of the tumour, together with the	
		behaviour (malignant or benign).	
12	Total number	The total number of cores or biopsy	FORMAT: N
	of cores	samples taken during a TRUS or	VALUES:
		transperineal biopsy.	Total number of cores
			-2=No pathology report
13	Number of	Cores refer to the biopsy samples	FORMAT: N
	positive cores	(derived from the needle biopsies) in	VALUES:
		specimen jars. A specimen jar may	Number of positive cores
		contain one or more cores. This data	-2=No pathology report
		field refers to the number of cores or	
		biopsy samples taken that have a	
		Gleason score during a TRUS or	
		transperineal biopsy.	



	,		
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
		and the control and the contro	VALUES:
			Valid date
26	Diagnosis MRI	If a MRI scan was performed at	FORMAT: N
	status	diagnosis	VALUES:
	otatao	alagricolo	0=No
			1=Yes
			9=Not known
27	MRI Date	Date of MRI scan at time of diagnosis	FORMAT: YYYY-MM-DD
	WIN Bate	Date of With Scarrat time of diagnosis	VALUES:
			Valid date
28	PET status	If a PET scan was done to assist in N	FORMAT: String
20	1 L1 Status	and M staging	VALUES:
		and w staging	True=Yes
			False=No
			1 dtse-110
29	PIRADS score	The Prostate Imaging Reporting and	FORMAT: N
	1 110 100 00010	Data System (PI-RADS) reports how	VALUES:
		likely that a suspicious area on an	1=Very low
		MRI is a clinically significant cancer.	2=Low
		The score is taken from the latest	3=Intermediate (undetermined)
		MRI before the date of diagnosis.	4=High
		With before the date of diagnosis.	5=Very High
			3-Very riigii
30	Date of PET	Date of PET scan at diagnosis	FORMAT: YYYY-MM-DD
	scan		VALUES:
			Valid date
31	Radiology test	If no scans or radiology tests were	FORMAT: String
01	status	done	VALUES:
	Status	done	True=No radiology test done
			False=No (not checked)
			1 dt3c=140 (flot checked)
32	Other imaging	If another scan was performed to	FORMAT: String
	status	assist N & M staging	VALUES:
33	Imaging	If unknown radiology tests were	FORMAT: String
	unknown	conducted to assist staging	VALUES:
	diminown		True=Yes (not known)
			False=No (known)
34	Lymphovascula	Refers to cancer (tumour) spreading	FORMAT: N
•	r invasion	to lymphatic and/or blood vessels	VALUES:
		to Griphatio alia, or blood voccio	0=No
			1=Yes
			-1=Not stated
			-2=No pathology report
			-3=Data collected prior to database
			-0-Data collected prior to database



ID	Variable Name	Variable Description	Variable Formet /Values
<b>ID</b> 35	Variable Name	Variable Description	Variable Format / Values
35	Perineural	Refers to cancer (tumour) spreading,	FORMAT: N VALUES:
	invasion	growing, infiltrating, or invading to a	
		space around a nerve or within a	0=No
		nerve.	1=Yes
			-1=Not stated
			-2=No pathology report
			-3=Data collected prior to database
36	Seminal vesicle	Refers to the presence of prostate	FORMAT: N
	invasion	cancer in the areolar connective	VALUES:
		tissue around the seminal vesicles	0=No
		and outside the prostate.	1=Yes
			-1=Not stated
			-2=No pathology report
			-3=Data collected prior to database
			o bata contested prior to database
	_		
37	Extraprostatic	Refers to the cancer (tumour)	FORMAT: N
	invasion	extending outside the capsule but	VALUES:
		NOT into the seminal vesicle.	0=No
			1=Yes
			-1=not stated
			-2=no pathology report
			-3=data collected prior to database
38	T stage	A categorical description ranging	FORMAT: N
		from TX to T4, depending on the	VALUES:
		level of involvement of cancer, felt in	1=TX (cannot be assessed)
		the prostate during a digital rectal	2=T0
		examination (DRE). This should NOT	3=T1
		be confused with the pathological T	4=T1a
		obtained within pathology reports.	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	Variable Description  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



#### **Table 3 Treatments**

ID	Variable Name	Variable Description	/ariable Format / Values
Trea	atment - 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 Focalgland ablation.	FORMAT: DD/MM/YYYY VALUES: Valid date
Tre	atment - Surgery	1	
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



ID	Variable Name	Variable Description	/ariable Format / Values
4	Surgery PSA	If the participant's PSA was	FORMAT: N
	status	collected prior to surgery	VALUES:
		, , ,	1=Taken
			-1=Not Stated
			'-2=Not Taken
5	Surgery PSA	PSA level in nanograms of PSA per	FORMAT: N-NNNNN.NN
	level	millilitre of blood (ng/mL)	VALUES:
6	Surgery PSA	Date the PSA level was collected	FORMAT: YYYY-MM-DD
	date		VALUES:
			Valid date
7	Surgery	If surgery indicated the presence of	FORMAT: N
	presence of	a tumor.	VALUES:
	tumour		0=No
			1=Yes
			9=Not known
			-1=Collected prior to new database
8	Surgery	If the cancer (tumour) extended	FORMAT: N
	extraprostatic	outside the capsule but NOT into the	VALUES:
	invasion	seminal vesicle.	0=No
			1=Yes
			-1=Not stated
			-2=No pathology report -3=Data collected prior to database
			-3-Data confected prior to database
		15.1	FORMAT N
9	Surgery	If the prostate cancer invades the	FORMAT: N
	seminal vesicle	muscular wall of the seminal vesicle.	VALUES: 0=No
	invasion		1=Yes
			-1=Not stated
			-2=No pathology report
			-3=Data collected prior to database
10	Surgery	If the cancer (tumour) was spreading,	FORMAT: N
	perineural	growing, infiltrating, or invading to a	VALUES:
	invasion	space around a nerve or within a	0=No
		nerve.	1=Yes
			-1=Not stated
			-2=No pathology report
4.4			-3=Data collected prior to database
11	Surgery nerve	Nerve preservation during surgery to	FORMAT: N
	sparing status	assess any implication on the level of	VALUES:
		bother from side effects the patient	1=Non-nerve-sparing
		will experience	2=Nerve-sparing
			-1=Unknown
			-3=Collected prior to DB build



ID	Variable Name	Variable Description	/ariable 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)



10	V : II-N	V : 11 B : ::	/ · · · · · · · · · · · · · · · · · · ·
ID 10	Variable Name		/ariable Format / Values
16	Surgery	The Gleason score (primary) is a	FORMAT: N
	primary	number that refers to the most	VALUES:
	Gleason score	dominant or common pattern of	1=1
		cancer found in the prostate	2=2
		specimen.	3=3 4=4
			5=5
			-1=Not stated
			-2=No pathology report
			-3=Insufficient sample
17	Surgery	The Gleason score (secondary) is a	FORMAT: N
1.7	secondary	number that refers to the second	VALUES:
	Gleason score	most common or dominant pattern or	1-5
		may be the highest grade found	-1=Not stated
		within the specimen, depending on	-2=No pathology report
		the pathology guidelines used.	-3=Insufficient sample
		. 37 5	·
18	Surgery total	The Gleason sum is a measure of the	FORMAT: N
10	Gleason score	aggressiveness of prostate cancer	VALUES:
	Grouper Coord	and is the sum of two numbers (the	1-6=Low/very low
		primary and secondary grades).	7=Intermediate
		, , , , , , , , , , , , , , , , , , , ,	8-10=High/very high
			-1=Not stated
			-2=No pathology report
			-3=Insufficient sample
19	Pathological	The edge or border of the tissue	FORMAT: N
19	margins	removed in cancer surgery. Present:	VALUES:
	margins	The margin is positive or involved if	1=Present
		the cancer cells are at the edge of	2=Absent
		the tissue, suggesting that not all of	3=Abuts margin
		the cancer is removed.	4=Equivocal: pathological
			(insufficient sample to enable
			definitive margin)
			5=Equivocal: inadequate/unclear
			documentation on the path report
			-1=Equivocal: margin not stated
	1.0	N. I. G.I	-2=No pathology report
20	Margin status	Number of places the margin has	FORMAT: N
	focality	been crossed in a prostatectomy	VALUES:
		specimen. If pathological margins	1=Focal
		are positive, the status of the focality needs to be collected.	2=Multi-focal -1=Unknown
		Focal: If the margin is only crossed	-3=Collected prior to DB build
		once (e.g. left apex)(one foci/tumour)	-3-Collected prior to DD build
		Multi-focal: If the margin is crossed	
		in more than one place (e.g. left apex	
		and right base) (1 foci/tumour)	
		and the state of t	



ID	Variable Name	Variable Description	/ariable Format / Values
21	Focal extensive	If the margins are reported as	FORMAT: N
<i>-</i> '	margins	'positive' or 'involved', specify the	VALUES:
	margins	extent or involvement of the margin.	1=≤1mm (focal)
		It is either focal (≤ 1 mm) or extensive	2=>1mm (local)
		(> 1 mm).	-1=Not stated/unknown
		(~ i iiiiii).	-2=no pathology report
Tres	ıtment - Radioth	erany	-2-110 patriology report
1	Radiotherapy	If the participant underwent	FORMAT: N
'	status	radiotherapy treatment	VALUES:
	Status	radiotherapy treatment	0=No
			1=Yes
			2=Pending
			9=Not known
2	External beam	Use of external beam radiotherapy	FORMAT: N
_	radiotherapy	Osc of external bearing another apy	VALUES:
	таспостиетару		0=No
			1=Yes
			9=Not known
3	Unknown	If the radiotherapy type is unknown	FORMAT: N
	radiotherapy	if the radiotherapy type is anknown	VALUES:
	radiotriciapy		0=No
			1=Yes
4	Total dose	Cumulative prescribed dose of EBRT	FORMAT: NN
4	Total dose	(Gy) administered during the course	VALUES:
		of treatment for prostate cancer.	VALUES.
5	Total dose	If the total dose (Gy) for	FORMAT: String
3	unknown	primary/salvage radiotherapy is	VALUES:
	ulikilowii	unknown	True=Dose Unknown
		unknown	False=Dose Known
6	Number of	The total number of fractions for	FORMAT: NN
0	fractions	primary/salvage radiotherapy	VALUES:
7	Number of	If the total number of fractions for	FORMAT: N
′	fractions	primary/salvage radiotherapy is	VALUES:
	unknown	unknown	0=Fractions Known
	ulikilowii	unknown	1=Fractions Unknown
8	Start date of	The start date of radiotherapy.	FORMAT: YYYY-MM-DD
8	radiotherapy	The start date of radiotherapy.	VALUES:
	таспотпетару		Valid date
9	Stop date of	The stop date of completed	FORMAT: YYYY-MM-DD
J	radiotherapy	radiotherapy treatment	VALUES:
	raulotrierapy	тайонівтару пеаннені	VALUES: Valid date
10	Padiothoras:	If the course of radiotherapy is still in	FORMAT: N
10	Radiotherapy	If the course of radiotherapy is still in	VALUES:
	ongoing	progress or has been completed.	0=Completed
			1=Treatment ongoing
11	Padiatharany	If the participant's DSA was	FORMAT: N
11	Radiotherapy	If the participant's PSA was collected prior to the start date of	
	PSA status	•	VALUES:
		radiotherapy	1=Taken
			-1=Not Stated
10	Da ali a tha consider	DCA I and in a second of DCA	'-2=Not Taken
12	Radiotherapy	PSA level in nanograms of PSA per	FORMAT: N-NNNNN.NN
L	PSA level	millilitre of blood (ng/mL)	VALUES:



			GOVERNMENT
ID	Variable Name		Variable Format / Values
13	Radiotherapy	Date the PSA level was collected	FORMAT: YYYY-MM-DD
	PSA date		VALUES:
			Valid date
Trea	tment - Surveillar	nce (Active and Watchful Waiting)	
1	Active	If the participant underwent active	FORMAT: N
•	surveillance	surveillance	VALUES:
	status	car voltarios	0=No
	Status		1=Yes
			9=Not known
2	Watchful	If the participant underwent	FORMAT: N
_	waiting status	watchful waiting	VALUES:
	waiting status	waterrut waiting	0=No
			1=Yes
•	D	Did it is a second	9=Not known
3	Date of	Date the participant patient made	FORMAT: YYYY-MM-DD
	watchful	the decision to be monitored by	VALUES:
	waiting or	active surveillance/watchful waiting.	Valid date
	active	This date is usually an approximate	
	surveillance	date and is not a mandatory field.	
Trea	atment - ADT		
1	Androgen	If the participant underwent	FORMAT: N
	deprivation	androgen deprivation therapy	VALUES:
	therapy status		0=No
			1=Yes
			2=Pending
			9=Not known
2	ADT type	Type of androgen deprivation	FORMAT: N
_	7.2. 3/60	therapy.	VALUES:
		thorapy.	1=Chemical
			2=Surgical
3	ADT number	The sequence number in the order of	FORMAT: N
3	ADTITIONDE	androgen deprivation therapies a	VALUES:
		patient has had (maximum of 8).	1-8
4	ADT agent	The chemical agent used for	FORMAT: NN
4	ADI agent		
		androgen deprivation therapy.	VALUES:
			Chemical agents are listed by
			molecule (brand name). See
_	0	T	Appendix 2.
5	Start date of	The start date of androgen	FORMAT: YYYY-MM-DD
	ADT	deprivation therapy. This can be a	VALUES:
		date before the Date of Diagnosis or	Valid date
		a future date if pending.	
6	Stop date of	The stop date of androgen	FORMAT: YYYY-MM-DD
	ADT	deprivation therapy	VALUES:
			Valid date
7	Treatment	ADT ongoing indicates if the ADT is	FORMAT: N
	ongoing	still in progress or has been	VALUES:
		completed.	0=Completed
			1=Treatment ongoing
8	ADT PSA	If the participant's PSA was	FORMAT: N
5	status	collected prior to the start of ADT	VALUES:
	วเสเนอ	collected prior to the start of ADT	1=Taken
			-1=Not Stated
			'-2=Not Taken



ID	Variable Name	Variable Description	/ariable Format / Values	
9	ADT PSA level	PSA level in nanograms of PSA per	FORMAT: N-NNNNN.NN	
		millilitre of blood (ng/mL)	VALUES:	
10	ADT PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD	
	7.511 071 0010	Bate the Feyttevet was selected	VALUES:	
			Valid date	
Tros	atment - TURP		valia date	
1	TURP status	If a transurethral resection of the	FORMAT: N	
'	TONE Status	prostate (TURP) was performed	VALUES:	
		prostate (TONF) was performed	0=No	
			1=Yes	
2	Date of TURP	Date of the TURP procedure	FORMAT: YYYY-MM-DD	
	Date of TORP	Date of the Toke procedure	VALUES:	
	TUDD	D (1	Valid date	
3	TURP presence	Presence of tumour	FORMAT: N	
	of tumour		VALUES:	
			0=No	
			1=Yes	
			9=Not Known	
			-1=Collected prior to new database	
4	TURP histology	The codes are based on the	FORMAT: NNNNN	
	type	International Classification of	VALUES:	
		Diseases for Oncology (ICD-0-3)	ICD-0-3 morphology codes. See	
		morphology codes. The	Appendix 1.	
		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).		
5	TURP primary	The Gleason score (primary) is a	FORMAT: N	
	Gleason score	number that refers to the most	VALUES:	
		dominant or common pattern of	1-5	
		cancer found in the prostate	-1=Not stated	
		specimen.	-2=No pathology report	
			-3=Insufficient sample	
6	TURP	The Gleason score (secondary) is a	FORMAT: N	
	secondary	number that refers to the second	VALUES:	
	Gleason score	most common or dominant pattern or	1-5	
		may be the highest grade found	-1=Not stated	
		within the specimen, depending on	-2=No pathology report	
		the pathology guidelines used.	-3=Insufficient sample	
		,		
7	TURP sum	The Gleason sum is a measure of the	FORMAT: N	
/				
	Gleason score	aggressiveness of prostate cancer	VALUES:	
		and is the sum of two numbers (the	1-6=Low/very low	
		primary and secondary grades).	7=Intermediate	
			8-10=High/very high	
			-1=Not stated	
			-2=No pathology report	
			-3=Insufficient sample	
Treatment - Unknown and Other				



ID	V · II N	V : 11 B : ::	V : 11 E / / / 1
ID	Variable Name	Variable Description	Variable Format / Values
2	Referred	If the participant was referred for	FORMAT: N
	treatment	treatment.	VALUES:
	status		0=No
			1=Yes
3	Other systemic	If the participant underwent other	FORMAT: N
	therapies	administered systemic therapies	VALUES:
	status		0=No
			1=Yes
			2=Pending
			9=Not known
4	Unknown	If the participant underwent	FORMAT: N
	treatment	unknown treatment	VALUES:
	status		0=No
			1=Yes
5	Other	Description of the other treatment	FORMAT: String
	treatment type	type	VALUES:
		3,60	.,,2020.
6	Start date of	The start date of other treatment.	FORMAT: YYYY-MM-DD
	other treatment	This must be after date of diagnos	is VALUES:
		and can only be a future date if	Valid date
		pending.	
7	Stop date of	The stop date of other treatment	FORMAT: YYYY-MM-DD
	other treatment	•	VALUES:
			Valid date
8	Other	Indicates if the treatment is still in	FORMAT: N
	treatment	progress or has been completed.	VALUES:
	ongoing	p of the second	0=Completed
			1=Treatment ongoing
9	Start date of	The start date of other systemic	FORMAT: YYYY-MM-DD
	other systemic	therapies	VALUES:
	therapies	and aprec	Valid date
	tricrapies		vatia date
10	Other	If the participant's PSA was	FORMAT: N
	treatment PSA	collected prior to the start date of	VALUES:
	status	other treatment	1=Taken
	Status	other treatment	-1=Not Stated
			'-2=Not Taken
11	Other	PSA level in nanograms of PSA pe	
11	treatment PSA	millilitre of blood (ng/mL)	VALUES:
	level	mittititie of blood (fig/file)	VALUES.
12	Other	Date the PSA level was collected	FORMAT: YYYY-MM-DD
12	treatment PSA	Date the FSA level was collected	VALUES:
	date		Values: Valid date
Tues		)	valiu uale
	Brookythoropy		EODMAT: N
1	Brachytherapy	If the participant underwent	FORMAT: N
	status	brachytherapy	VALUES:
			0=No
			1=Yes
			2=Pending
			9=Not known



ID	Variable Name		Variable Format / Values
2	LDR	If a low dose rate of brachytherapy	FORMAT: N
	brachytherapy	was administered	VALUES:
	status		0=No
			1=Yes
3	HDR	If a high dose rate of brachytherapy	FORMAT: N
	brachytherapy	was administered	VALUES:
	status		0=No
			1=Yes
4	Unknown type	If the brachytherapy type is unknown	FORMAT: N
	brachytherapy	, , , , , ,	VALUES:
			0=No
			1=Yes
5	Date of	The date of brachytherapy. The date	FORMAT: YYYY-MM-DD
	brachytherapy	must occur after the date of	VALUES:
	(	diagnosis and can only be a future	Valid date
		date if pending.	
		adto ii polidiligi	
6	Brachytherapy	Total Dose (Gy) for first course of	FORMAT: N
	total dose	Brachytherapy	VALUES:
	10 1011 0.000	2. 0.0.1, 0.10.0.py	77.2020.
7	Brachytherapy	If the participant's PSA was	FORMAT: N
	PSA status	collected prior to the start date of	VALUES:
		brachytherapy	1=Taken
			-1=Not Stated
			'-2=Not Taken
8	Brachytherapy	Date the PSA level was collected	FORMAT: YYYY-MM-DD
	PSA date		VALUES:
			Valid date
			valid dato
9	Brachytherapy	PSA level in nanograms of PSA per	FORMAT: N-NNNNN.NN
	PSA level	millilitre of blood (ng/mL)	VALUES:
	tment - Focal Gla		
1	Focal gland	If the participant underwent focal	FORMAT: N
	ablation	gland ablation therapy	VALUES:
	therapy		0=No
			1=Yes
			2=Pending
2	Date of focal	The date of focal-gland ablation	FORMAT: YYYY-MM-DD
	gland ablation	therapy. The date must be after date	VALUES:
	therapy	of diagnosis and can only be a future	Valid date
		date if 'Pending'	
3	Focal gland	If the participant's PSA was	FORMAT: N
	ablation	collected prior to the start date of	VALUES:
	therapy PSA	focal gland ablation therapy	1=Taken
	status		-1=Not Stated
			'-2=Not Taken
	I	1	



ID	Variable Name	Variable Description	/ariable 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-NNNNNNN
5	Focal gland ablation therapy PSA date	Date the PSA level was collected	FORMAT: YYYY-MM-DD VALUES: Valid date
Trea	tment - Chemothe	erapy	
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 f up	ollow FORMAT: N VALUES: 0=No 1=Yes



ID	Variable Name	Variable Description	Variable Format / Values
3	Lost to follow	Reason for lost to follow up at 12	FORMAT: N
	up reason	month follow up for EPIC-26 survey	VALUES:
	ap reason	month follow up for El 10 20 salvey	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	Description of the reason the	FORMAT: N
4		participant was lost to follow up if	VALUES:
	up reason other	1	VALUES.
		lost to follow up reason is 'Other'	
5	EPIC-26	Over the past 4 weeks, how often	FORMAT: N
	Question 1	have you leaked urine? (Patient-	VALUES:
	Urine leakage	Reported)	1=More than once a day
		1	2=About once a day
			3=More than once a week
			4=About once a week
			5=Rarely or never
			O-Marety of flever
6	EPIC-26	Question 2. Which of the following	FORMAT: N
	Question 2	best describes your urinary control	VALUES:
	Urinary control	during the last 4 weeks? (Patient-	1=No urinary control whatsoever
		Reported)	2=Frequent dribbling
			3=Occasional dribbling
			4=Total control
			-1=Participant declines to answer



ID	Variable Name	Variable Description	/ariable 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/we ak 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



ID	Variable Name	Variable Description	/ariable Format / Values
13	EPIC-26	Question 5. Overall, how big a	FORMAT: N
10	Question 5	problem has your urinary function	VALUES:
	Urinary	been for you during the last 4	1=No problem
	problem	weeks? (Patient-Reported)	2=Very small problem
	problem	weeks: (Fatient-Neported)	3=Small problem
			·
			4=Moderate problem
			5=Big problem
1.4	EDIO OC	0 - 1 - 0 - 1 - 1 1	-1=Participant declines to answer
14	EPIC-26	Question 6A. How big a problem, if	FORMAT: N
	Question 6A	any, has each of the following been	VALUES:
	Bowel urgency	for you? Urgency to have a bowel	1=No problem
		movement. (Patient-Reported)	2=Very small problem
			3=Small problem
			4=Moderate problem
			5=Big problem
			-1=Participant declines to answer
15	EPIC-26	Question 6B. How big a problem, if	FORMAT: N
	Question 6B	any, has each of the following been	VALUES:
	Bowel	for you? Increased frequency of	1=No problem
	frequency	bowel movements (Patient-	2=Very small problem
		Reported)	3=Small problem
			4=Moderate problem
			5=Big problem
			-1=Participant declines to answer
16	EPIC-26	Question 6C. How big a problem, if	FORMAT: N
	Question 6C	any, has each of the following been	VALUES:
	Bowel control	for you? Losing control of your stools	1=No problem
		(Patient-Reported)	2=Very small problem
			3=Small problem
			4=Moderate problem
			5=Big problem
			-1=Participant declines to answer
17	EPIC-26	Question 6D. How big a problem, if	FORMAT: N
	Question 6D	any, has each of the following been	VALUES:
	Bowel bleeding	for you? Bloody stools (Patient-	1=No problem
		Reported)	2=Very small problem
			3=Small problem
			4=Moderate problem
			5=Big problem
			-1=Participant declines to answer
18	EPIC-26	Question 6E. How big a problem, if	FORMAT: N
	Question 6E	any, has each of the following been	VALUES:
	Bowel	for you? Abdominal/Pelvic/Rectal	1=No problem
	abdominal pain	pain (Patient-Reported)	2=Very small problem
		pa (i dilotte responted)	3=Small problem
			4=Moderate problem
			5=Big problem
			-1=Participant declines to answer
			- i – i di ticipant decimes to answel



ID	Variable Name	Variable Description	/ariable Format / Values
19	EPIC-26	Question 7. Overall, how big a	FORMAT: N
19			
	Question 7	problem have your bowel habits	VALUES:
	Bowel problem	been for you during the last 4	1=No problem
		weeks? (Patient-Reported)	2=Very small problem
			3=Small problem
			4=Moderate problem
			5=Big problem
			-1=Participant declines to answer
20	EPIC-26	Question 8A. How would you rate	FORMAT: N
	Question 8A	each of the following during the last	VALUES:
	Erectile ability	4 weeks? Your ability to have an	1=Very poor to none
		erection? (Patient-Reported)	2=Poor
			3=Fair
			4=Good
			5=Very good
			-1=Participant declines to answer
21	EPIC-26	Question 8B. How would you rate	FORMAT: N
	Question 8B	each of the following during the last	VALUES:
	Erectile orgasm	4 weeks? Your ability to reach	1=Very poor to none
	Li ootito organii	orgasm (climax)? (Patient-Reported)	2=Poor
		organi (etimax): (i ationi rioportoa)	3=Fair
			4=Good
			5=Very good
			-1=Participant declines to answer
22	EPIC-26	Question 9. How would you describe	FORMAT: N
22		_	
	Question 9	the usual QUALITY of your erections	VALUES:
	Erectile quality	during the last 4 weeks? (Patient-	1=None at all
		Reported)	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. How would you describe		FORMAT: N
	•		VALUES:
		,	1=I NEVER had an erection when I
	frequency	Reported)	wanted one
		Question 10. How would you describe the FREQUENCY of your erections during the last 4 weeks? (Patient-requency Reported)	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. Overall, how would you	FORMAT: N
	Question 11	rate your ability to function sexually	VALUES:
	Sexual	during the last 4 weeks? (Patient-	1=Very poor to none
	functionality	Reported)	2=Poor
			3=Fair
			4=Good
			5=Very good
			-1=Participant declines to answer
			i i di ticipant dectines to answel



D Variable Name   Variable Description   Variable Format / Value	
Question 12 Sexual problem lack of sexual function been for you during the last 4 weeks? (Patient-Reported)  Problem has your sexual function or lack of sexual function been for you during the last 4 weeks? (Patient-Reported)  2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem  26 EPIC-26 Question 13A. How big a problem FORMAT: N	es to answer
Sexual problem lack of sexual function been for you during the last 4 weeks? (Patient-Reported)  Reported)  -1=Participant declin 1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem  26 EPIC-26 Question 13A. How big a problem FORMAT: N	es to answer
during the last 4 weeks? (Patient-Reported)  1=No problem 2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem  26 EPIC-26 Question 13A. How big a problem FORMAT: N	
Reported)  2=Very small problem 3=Small problem 4=Moderate problem 5=Big problem  26 EPIC-26 Question 13A. How big a problem FORMAT: N	
3=Small problem 4=Moderate problem 5=Big problem Compared to the problem of the p	m
4=Moderate problem 5=Big problem Comparison 13A. How big a problem FORMAT: N	
5=Big problem Control	n
26 EPIC-26 Question 13A. How big a problem FORMAT: N	11
1 Unoction 120 I during the last Awards if any beautiful IEC	
Question 13A during the last 4 weeks, if any, has VALUES: Hot flushes each of the following been for you? -1=Participant declin	oo to opower
	ies to aliswei
Hot flushes (Patient-Reported) 1=No problem	
2=Very small proble	m
3=Small problem	
4=Moderate problen	n
5=Big problem	
27 EPIC-26 Question 13B. How big a problem FORMAT: N	
Question 13B during the last 4 weeks, if any, has VALUES:	
Breast problem   each of the following been for you?   -1=Participant declin	es to answer
Breast tenderness/enlargement 1=No problem	
(Patient-Reported) 2=Very small problem	m
3=Small problem	
4=Moderate problen	n
5=Big problem	
28 EPIC-26 Question 13C. How big a problem FORMAT: N	
Question 13C during the last 4 weeks, if any, has VALUES:	
Depression each of the following been for you? -1=Participant declin	es to answer
Feeling depressed (Patient- 1=No problem	
Reported) 2=Very small proble	m
3=Small problem	
4=Moderate problem	n
5=Big problem	
29 EPIC-26 Question 13D. How big a problem FORMAT: N	
Question 13D during the last 4 weeks, if any, has VALUES:	
Lack of energy each of the following been for you? -1=Participant declin	es to answer
Lack of energy (Patient-Reported) 1=No problem	ics to answer
2=Very small problem	m
3=Small problem	111
4=Moderate problem	n
·	l I
30 EPIC-26 Ouestion 13E. How big a problem FORMAT: N	
Question 13E during the last 4 weeks, if any, has VALUES:	
Weight each of the following been for you? -1=Participant declin	ies to answer
changes Change in body weight (Patient- 1=No problem	
Reported) 2=Very small problem	m
3=Small problem	
4=Moderate problen	n
5=Big problem	



ID	Variable Name	Variable Description	/ariable Format / Values
31	LIBIDO	Question 1: During the last 4 weeks,	FORMAT: N
	Question 1	to what extent were you interested	VALUES:
	Sexual interest	in sex? (Patient-Reported)	0=Not at all
		in coxt (i differ topol tod)	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: Have you used any	FORMAT: N
32	Question 2 Use medications or devices to aid or improve erections? (Patient-	VALUES:	
			0=No
	or erectile aids	Reported)	1=Yes
		Reported)	-1=Participant declines to answer
			-3=Collected prior to DB build
33	LIBIDO	Question 3A: For each of the	FORMAT: N
33	Question 3A	following medicines or devices,	VALUES:
	Erectile tablets	,	0=Have not tried it
	crectite tablets	please indicate whether or not you	
		have tried or currently use it to	1=Tried it but was not helpful
		improve your erections: Viagra or	2= It helped but I am not using it now
		another pill (Patient-Reported)	3=It helped and I use it sometimes
			4=It helped and I use it always
			-1=Participant declines to answer
0.4	LIDIDO	0 1 00 5	-3=Collected prior to DB build
34	LIBIDO	Question 3B: For each of the	FORMAT: N
	Question 3B	following medicines or devices,	VALUES:
	Erectile MUSE	please indicate whether or not you	0=Have not tried it
	suppository	have tried or currently use it to	1=Tried it but was not helpful
		improve your erections: Muse (intra	2=It helped but I am not using it now
		urethral alprostadil suppository)	3=It helped and I use it sometimes
		(Patient-Reported)	4 It helped and I use it always
			-1=Participant declines to answer
25	LIDIDO	O	-3= Collected prior to DB build FORMAT: N
35	LIBIDO	Question 3C: For each of the	
	Question 3C	following medicines or devices,	VALUES:
	Erectile	please indicate whether or not you	0=Have not tried it
	injectionables	have tried or currently use it to	1=Tried it but was not helpful
		improve your erections: Penile	2=It helped but I am not using it now
		injection therapy (such as caverject)	3=It helped and I use it sometimes
		(Patient-Reported)	4 It helped and I use it always
			-1=Participant declines to answer
20	LIDIDO	Fan and of the fall and an arrangle to a	-3=Collected prior to DB build
36	LIBIDO	For each of the following medicines	FORMAT: N
	Question 3D	or devices, please indicate whether	VALUES:
	Erectilke	or not you have tried or currently use	0=Have not tried it
	vacuum devices	it to improve your erections: Vacuum	1=Tried it but was not helpful
		erection device (such as erectaid)	2=It helped but I am not using it now
		(Patient-Reported)	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



ID	Variable Name	Variable Description	Variable Format / Values
37	LIBIDO	Question 3E: For each of the	FORMAT: N
	Question 3E	following medicines or device	es, VALUES:
	Erectile other	please indicate whether or no	ot you 0=Have not tried it
	medication/devi	have tried or currently use it t	to 1=Tried it but was not helpful
	ce	improve your erections: Other	er 2=It helped but I am not using it now
		medication/device (Patient-	3=It helped and I use it sometimes
		Reported)	4=It helped and I use it always
			-1=Participant declines to answer
			-3=Collected prior to DB build



#### Appendix 1 - Residential/state/territory codes

1=NSW 10=Overseas resident 19=Wellington

2=VIC 11=Northland 20=Nelson-Marlborough

3=QLD 12=Auckland 21=Manawatu

4=SA 13=Waikato 22=South Canterbury

5=WA 14=Bay of Plenty 23=West Coast 6=TAS 15=Gisborne 24=Canterbury

7=NT 16=Hawke's Bay 25=Otago

8=ACT 17=Taranaki 26=Southland81403=Adenocarc

9=Unknown 18=Wairarapa inoma

#### 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