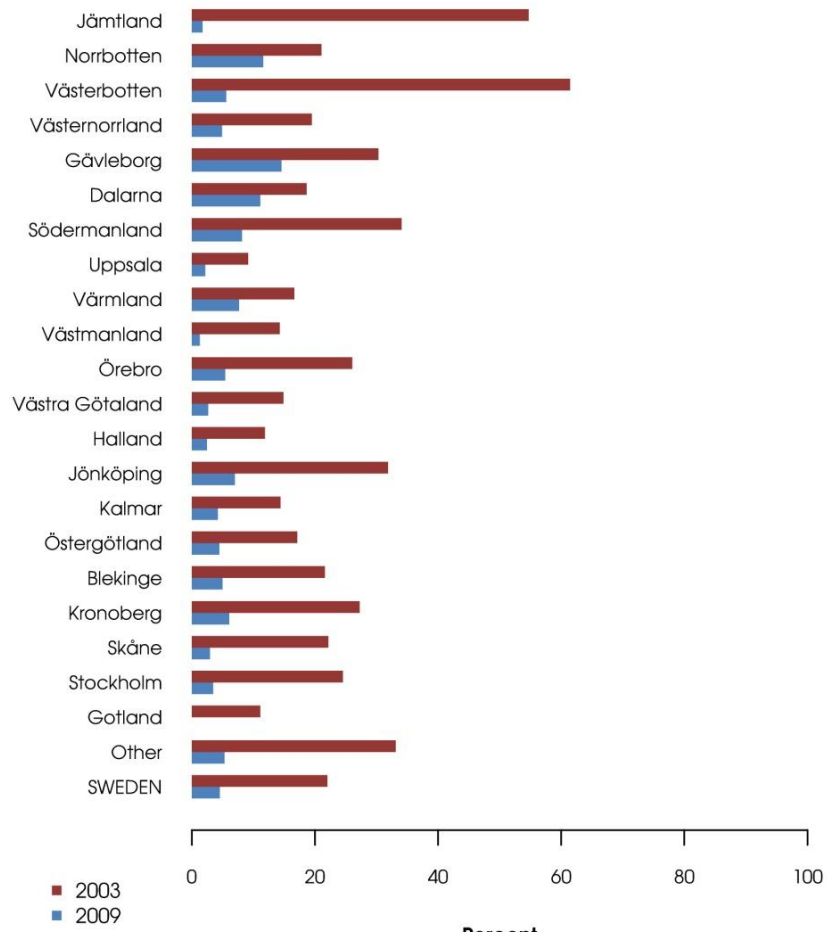


## Online Appendix

**Figure 1:** Distribution by county of proportion of men with low-risk prostate cancer who underwent a bone scan in 2003 and 2009



**Table 1** Information on diagnostic procedures and related information registered in NPCR.

Variable		Availability (calendar years)	Mean Capture Ratio	Capture Ratio 2009
Personal identification number		1993-	100 %	100 %
Code for the reporting hospital or clinic		1993-	> 99 %	> 99 %
Initial cause for work-up	Main reason for the initiation of the medical investigation that led to the prostate cancer diagnosis Available alternatives: a. PSA-screening as part of a health check-up for a man without lower urinary tract symptoms (LUTS) b. LUTS c. Other symptoms	2000- (2004- distinction between LUTS and other symptoms)	93 %	97 %
Date for the first visit to a urology specialist		2009-	> 99 %	> 99 %
Referral	Was the investigation leading up to prostate cancer diagnosis initiated by a referral to a urologist? Yes/No	2009-	96 %	96 %
Date of referral	The date when the letter of referral was written	2009-	93 %	93 %
Morphological confirmation of diagnosis	Available alternatives: a. Cytology b. Histology c. Clinical diagnosis	1997-	97 %	100 %
Date of diagnosis	For histology/cytology confirmed cases: the date of these examinations For clinically confirmed cases: the date of the clinical examination	1993-	100 %	100 %
Age at diagnosis		1993-	100 %	100 %
S-PSA	Serum level of prostate specific antigen (before diagnostic work-up)	1993-	97 %	98 %
Prostate volume	Determined by transrectal ultrasound (TRUS) or other radiologic examination	2007-*	84 %	87 %
PSA-density	Calculated as PSA/ TRUS volume	2007-*	84 %	86 %
TNM-stage (clinical)				
Tumour stage	T0, T1a, T1b, T1c, T2, T3, T4, Tx	1993-	> 99 % (Tx = 2%)	> 99 % (Tx = 2%)
Involvement of regional lymphnodes	N0, N1, Nx	1993-	99 % (Nx = 87 %)	> 99 % (Nx = 95 %)
Distant metastases	M0, M1, Mx	1993-	> 99 % (Mx = 60 %)	> 99 % (Mx = 76 %)
Tumour differentiation				
Gleason Grade 1		2000-	84 %	99 % (of patients with histology confirmed diagnosis)
Gleason Grade 2		2000-	84 %	99 % (of patients with histology confirmed diagnosis)
Gleason Score	= Gleason Grade 1 + Gleason Grade 2	1993-	93 %	99 % (of patients with histology confirmed diagnosis)
WHO Grade	G1, G2, G3, Gx	1993-	93 %	85 % (of patients with cytology confirmed diagnosis)
Tissue/cells from	a. Needle biopsy/core biopsy b. TUR-P (transurethral resection of the prostate) c. Fine-needle aspiration d. Other	2007-*	> 99 %	> 99 %
Number of core biopsies taken		2007-*	> 99 %	> 99 %
Number of core biopsies with cancer		2007-*	98 %	99 %
Total length of biopsies		2009-	60 %	60 %
Total length of cancer in biopsies		2009-	80 %	80 %

\* The Stockholm-Gotland healthcare region introduced the variable 2008

**Table 2** Information registered for primary treatment in the NPCR – completed or decided within six months following diagnosis

Variable	Availability (calendar years)	Mean Capture Ratio	Capture Ratio 2009
Personal identification number	1993-	100 %	100 %
Code for the reporting hospital or clinic	1993-	> 99 %	> 99 %
Date for decision of primary treatment	2007-*	97 %	97 %
Primary treatment strategy	Available alternatives: 1993-	98 %	99 %
	a. Treatment with curative intent		
	b. Conservative therapy (active surveillance or watchful waiting)		
	c. Palliative therapy		
	d. Missing due to early death		
Type of treatment with curative intent	Available alternatives: 1993-	98 %	97 %
	a. Radical prostatectomy		
	b. Radical prostatectomy + curative radiotherapy		
	c. Radiotherapy		
	d. Other type of curative treatment		
Type of conservative therapy	Available alternatives: 2007-*	97 %	96 %
	a. Active surveillance		
	b. Watchful waiting		
<b>Radical prostatectomy as primary treatment</b>			
Date of radical prostatectomy	2007-*	> 99 %	> 99 %
Type of radical prostatectomy	Available alternatives: 2007-*	100 %	100 %
	a. Retropubic		
	b. Laparoscopic		
	c. Robot-assisted laparoscopic		
Nerve saving	-2008 whether Nn Erigentes were intact postoperatively 2009- the preoperative nerve saving intent irrespective of the actual outcome 2007-*	88 %	89 %
	Available alternatives:		
	a. Yes, bilateral		
	b. Yes, unilateral		
	c. No		
	d. other alternative		
Tumour stage (pathological)	From the pathology report after the prostatectomy: pT0, pT2, pT3, pT3a, pT3b, pT4 2007-*	96 %	97 %
Radical extirpation	No (positive margin i.e when there is tumour tissue in the resection margin) a. Yes b. Unsure (when the pathologist expressed uncertainty) 2007-*	97 %	99 %
Postoperative Gleason Grade 1	2007-*	99 %	99 %
Postoperative Gleason Grade 2	2007-*	99 %	99 %
Postoperative Gleason Score	= Gleason Grade 1 + Gleason Grade 2 2007-*	99 %	99 %
Lymph node dissection	Yes/No 2009-	99 %	99 %
pN	Lymph node status postoperatively pN0, pN1, NX 2007-*	98 %	98 %
<b>Radiotherapy as primary treatment</b>			
Date for referral to radiotherapy	2007-*	94 %	96 %
Type of curative radiotherapy	a. External b. Brachytherapy c. Combination 2007-*	99 %	100 %
Neoadjuvant hormonal therapy	Hormonal therapy before radiotherapy. Yes/No 2007-*	84 %	91 %
Adjuvant therapy to patients treated with curative intent (prostatectomy/radiotherapy)	Given within 3 months postoperatively more than one alternative can be selected): a. No adjuvant therapy b. External radiotherapy c. GnRH analogue d. Antiandrogens e. Chemotherapy 2007-*	70 %	70 %
			( 92 % of patients treated with prostatectomy)
<b>Palliative therapy as primary treatment</b>			
Type of hormonal therapy	a. Orchiectomy b. GnRH analogue c. Antiandrogens d. Oestrogens e. Other 1993-	96 %	97 %

\* The Stockholm-Gotland health care region introduced the variable 2008

**Table 3** Registration by the oncology department of radiotherapy with curative intent, performed since 2008.

Variable	Definition	Capture Ratio 2009
Personal identification number		100 %
Date for treatment decision	When decided by an oncologist that radiotherapy would be performed	99 %
<b>Primary external radiotherapy</b>	Yes/No	97 %
Start date		> 99 %
Dose	Dose given per treatment occasion	> 99 %
	Dose total	> 99 %
Image guided radiotherapy	Yes/No	> 99 %
Intensity modulated radiotherapy	Yes/No	> 99 %
Inclusion of vesicles	Yes/No	> 99 %
Inclusion of lymph nodes	Yes/No	> 99 %
Boost	Yes/No	> 99 %
Start date		100 %
Source	a. HDR b. Protons c. Photons	100 %
Dose	Dose given per treatment occasion	100 %
	Dose total	100 %
Isotope	a. Iridium b. Other	100 %
Seeds	Yes/No	97 %
Start date		100 %
Dose	Total dose	100 %
Isotope	a. I-125 b. Palladium c. Other	100 %
<b>Postoperative radiotherapy</b>	Yes, adjuvant/Yes, salvage/No	97 %
Start date		100 %
Dose	Dose given per treatment occasion and dose total	100 %
Image guided radiotherapy	Yes/No	100 %
Intensity modulated radiotherapy	Yes/No	99 %
Inclusion of vesicles	Yes/No	100 %
Inclusion of lymph nodes	Yes/No	> 99 %
<b>MRI support</b>	Has MRI been used as support for definition of target? Yes/No	99 %
<b>Neo-/adjuvant hormone therapy</b>	Yes/No	97 %
<i>Before and during treatment</i>	Yes/No	> 99 %
Type	a. Antiandrogens b. GnRH analogue c. TAB	100 %
Duration of treatment	a. ≤ 6 months b. > 6 months	> 99 %
<b>After radiotherapy</b>	Yes/No	> 99 %
Type	a. Antiandrogens b. GnRH analogue c. TAB	100 %
Duration of treatment	a. ≤ 6 months b. > 6 months ≤ 18 months c. > 18 months ≤ 30 months d. > 30 months	97 %

**Table 4** Five-year follow up of prostate cancer patients with localized prostate cancer (T1 or T2 and MX or M0), and PSA < 20 µg/L and age ≤ 70 years at time of diagnosis for men diagnosed in 2003 and 2004\*.

Variable		Capture ratio
Personal identification number		100 %
<b>Conservative therapy</b>	Yes/No	> 99 %
Type of conservative therapy	Active surveillance	99 %
	a. Watchful waiting	
	b. Strategy not defined	
5- α-reductase-inhibitor given/TUR-P given	Yes/No	96 %
PSA-level	Serum levels of prostate specific antigen:	
	a. 2-4 years after diagnosis (and date)	78 %
	b. 5 years after diagnosis or when conservative therapy was terminated (and date)	72 %
Reason for termination of conservative therapy	If conservative therapy was terminated.	> 99 %
	a. Choice of the patient	
	b. PSA progress	
	c. Biopsy progress	
	d. Other sign of progress	
	e. Other reason	
<b>Completed active curative therapy</b>	Yes/No	> 99 %
<b>Radical prostatectomy</b>	Yes/No	> 99 %
Date of radical prostatectomy		> 99 %
Type of prostatectomy	a. Retropubic	> 99 %
	b. Laparoscopic	
	c. Robot-assisted laparoscopic	
Nerve saving	Nerve saving (Nn Erigentes) technique according to operation report.	65 %
	a. Yes, bilateral	
	b. Yes, unilateral	
	c. No	
Tumour stage (pathological)	From the pathology report after the prostatectomy:	93 %
	pT0, pT2, pT3, pT3a, pT3b, pT4	
Radical exstirpation	a. No (when there is tumour tissue left in the resection border)	97 %
	b. Yes	
	c. Unsure (when the pathologist expresses uncertainty)	
Postoperative Gleason Grade and Gleason Score	Gleason Grade 1+ Gleason Grade 2 = Gleason Score	94 %
Lymph node dissection	Yes/No**	47 %
pN	Lymph node status postop.	82 %
	pN0, pN1, NX	
<b>Radiotherapy</b>	Yes/No	> 99 %
Date for referral to radiotherapy		98 %
Type of radiotherapy	a. External	> 99 %
	b. Low dose brachytherapy with permanent seeds	
	c. High dose brachytherapy with isotope	
	d. Combination of external and high dose brachytherapy	
Neoadjuvant hormonal therapy	Yes/No and date started	89 %
Other curative treatment	Type and date started	
<b>Adjuvant therapy</b>	Yes/No	98 %
Type of adjuvant therapy	a. External radiotherapy***	100 %
	b. GnRH analogue	
	c. Antiandrogens	
	d. Chemotherapy	
	and date started	
<b>Palliative therapy</b>	Yes/No	> 99 %
Type of palliative therapy	a. Orchiectomy	100 %
	b. GnRH analogue	
	c. Antiandrogens	
	d. Estrogens	
	e. Other hormonal therapy	
	f. Chemotherapy	
	g. Other palliative therapy	
	and date started	
<b>Complications caused by primary therapy</b>	Yes/No	97 %
Operation due to complication	Yes/No	91 %
Type of surgical procedure	Code and date	97 %
Serious micturition problems	Yes/No	88 %
Serious bowel problems	Yes/No	84 %

Dilatation of urethral stricture	Yes/No	86 %
Other serious complication	Yes/No	89 %
<b>PSA-level relapse after curatively intended primary treatment</b>	If yes: Type? Yes/No	97 %
PSA nadir	Lowest PSA-level and date*	74 %
PSA relapse after prostatectomy	Two measurements $\geq 0.2\mu\text{g/L}$ and dates	99 %
PSA relapse after radiotherapy	Two measurements $\geq 0.2\mu\text{g/L}$ above PSA nadir and dates	86 %
<b>Secondary therapy</b>	Yes/No	> 99 %
External radiotherapy	Date	76 %
	Date of referral	95 %
Neoadjuvant hormonal therapy	Yes/No	91 %
	Start date	
Other curative treatment	Which and start date	80 %
Adjuvant therapy	Yes/No	96 %
Type of adjuvant therapy	a. GnRH analogue b. Antiandrogens c. Chemotherapy and start date for treatment	98 %
Palliative therapy	Yes/No	98 %
Type of palliative therapy	a. Orchiectomy b. GnRH analogue c. Antiandrogens d. Oestrogens e. Other hormonal therapy f. Chemotherapy g. Other palliative therapy and start date for treatment	100 %
<b>PSA-level relapse after curatively intended secondary treatment</b>	Yes/No	95 %
	Level and date	67 % (nadir) 100 % (PSA 1) 88 % (PSA 2)
<b>Tertiary therapy</b>	Yes/No	97 %
Type of tertiary treatment	a. Antiandrogens b. GnRH analogue c. Chemotherapy d. Other	100 %
<b>Overall progress</b>	Yes/No	93 %
Bone metastases	Yes/No/Not examined	97 %
Date for scintigram		92 %
Other metastases	Yes/No/Not examined	97 %
Localisation	Localisation of other metastases and date for diagnosis: a. lymph nodes b. liver c. lungs d. other	98 %
<b>Latest follow-up</b>	Follow-up visit with urologist or contact with prostate cancer nurse (telephone or mail)	
Date		95 %
Level of latest PSA measurement		96 %
Date of latest PSA measurement		96 %
Referred to primary health care for future follow-up	Yes/No and date for referral	92 %

\* In 1997-2002, the above information was also collected for men with the same inclusion criteria for a specific research project. Mean time after diagnosis was four years (1).

\*\* Eligible and registered cases in 2003: 2429/2873 (85% coverage) and for 2004 2687/3637 (74% coverage)

\*\*\*Referral for external radiotherapy must be made within 4 months after prostatectomy to be labelled as adjuvant therapy - if referred later it should be labelled as secondary therapy.

**Table 5** Descriptive statistics for prostate cancer patients and comparison cohorts registered in PCBaSe 2.0.

	Prostate cancer patients		Controls for case-control studies		Comparison cohort for prospective cohort studies	
	N=119,777		N=567,542		N=567,528	
<b>Age</b>						
Mean (SD)	71.2	(9.1)	71.1	(9.2)	71.1	(9.2)
<b>Year of prostate cancer diagnosis</b>						
1987-1996	14041	(11.7)				
1997-1999	18162	(15.2)				
2000-2002	22305	(18.6)				
2003-2006	37406	(31.2)				
2007-2009	27863	(23.3)				
<b>Gleason score<sup>1</sup></b>						
2-6	44183	(36.9)				
7	28825	(24.1)				
8-10	18699	(15.6)				
Missing	28070	(23.4)				
<b>Prostate cancer risk category (2)</b>						
Low risk	26232	(21.9)				
Intermediate risk	26733	(22.3)				
High risk	31803	(26.6)				
Regionally metastatic	9365	(7.8)				
Distant metastases	20955	(17.5)				
Missing data	4689	(3.9)				
<b>Prostate cancer treatment</b>						
Surveillance	31978	(26.7)				
Curative	35947	(30.0)				
Palliative	46613	(38.9)				
Missing due to early death	630	(0.5)				
Missing	4609	(3.8)				
<b>Socioeconomic status</b>						
White collar	57773	(48.2)	253345	(44.6)	253189	(44.6)
Blue collar	60274	(50.3)	298413	(52.6)	298304	(52.6)
Not gainfully employed/Missing	1730	(1.4)	15785	(2.8)	16035	(2.8)
<b>Civil status</b>						
Married	80150	(66.9)	362697	(63.9)	362341	(63.8)
Single	37776	(31.5)	201240	(35.5)	201581	(35.5)
Missing	1851	(1.5)	3606	(0.6)	3606	(0.6)
<b>Education</b>						
Low	53204	(44.4)	265508	(46.8)	265464	(46.8)
Middle	39247	(32.8)	184673	(32.5)	184472	(32.5)
High	21378	(17.8)	93807	(16.5)	93727	(16.5)
Missing	5948	(5.0)	23555	(4.2)	23865	(4.2)
<b>Country of origin</b>						
Sweden	111385	(93.0)	510340	(89.9)	510056	(89.9)
Other Scandinavian countries	3966	(3.3)	23583	(4.2)	23723	(4.2)
Europe	3171	(2.6)	22910	(4.0)	22946	(4.0)
Other	1249	(1.0)	10675	(1.9)	10760	(1.9)
Missing	6	(0.0)	35	(0.0)	43	(0.0)
<b>Charlson comorbidity index (3-4)</b>						
0	77866	(65.0)	365786	(64.5)	365189	(64.3)
1	21929	(18.3)	103562	(18.2)	103931	(18.3)
2	11695	(9.8)	55267	(9.7)	55255	(9.7)
3+	8287	(6.9)	42928	(7.6)	43153	(7.6)

1 Prior to 2000 Gleason scoring was based on the WHO classification system (5).

**Table 6** Descriptive statistics for cohorts of prostate cancer patients (index case) and their brothers registered in PCBaSe 2.0.

	Index case of prostate cancer N=23,079		Brothers without prostate cancer N=33,805		Brothers with prostate cancer N=2,184	
<b>Age</b>						
Mean (SD)	62.7	(5.9)	59.2	(7.9)	61.1	(5.7)
<b>Year of prostate cancer diagnosis</b>						
1996-1999	1687	(7.3)			34	(1.6)
2000-2002	3457	(15.0)			163	(7.5)
2003-2006	9218	(39.9)			853	(39.1)
2007-2009	8717	(37.8)			1134	(51.9)
<b>Gleason score<sup>1</sup></b>						
2-6	12415	(53.8)			1242	(56.9)
7	6309	(27.3)			619	(28.3)
8-10	2855	(12.4)			248	(11.4)
Missing	1500	(6.5)			75	(3.4)
<b>Prostate cancer risk category (2)</b>						
Low risk	8673	(37.6)			897	(41.1)
Intermediate risk	6379	(27.6)			655	(30.0)
High risk	4137	(17.9)			351	(16.1)
Regionally metastatic	1206	(5.2)			107	(4.9)
Distant metastases	2113	(9.2)			131	(6.0)
Missing data	571	(2.5)			43	(2.0)
<b>Prostate cancer treatment</b>						
Surveillance	4441	(19.2)			442	(20.2)
Curative	13962	(60.5)			1392	(63.7)
Palliative	3968	(17.2)			292	(13.4)
Missing due to early death	42	(0.2)			3	(0.1)
Missing	666	(2.9)			55	(2.5)
<b>Socioeconomic status</b>						
White collar	11876	(51.5)	15085	(44.6)	1165	(53.3)
Blue collar	11127	(48.2)	18312	(54.2)	1015	(46.5)
Not gainfully employed/Missing data	76	(0.3)	408	(1.2)	4	(0.2)
<b>Civil status</b>						
Married	16061	(69.6)	20740	(61.4)	1532	(70.1)
Single	7017	(30.4)	12241	(36.2)	613	(28.1)
Missing	1	(0.0)	824	(2.4)	39	(1.8)
<b>Education level</b>						
Low	8145	(35.3)	11851	(35.1)	794	(36.4)
Middle	9100	(39.4)	13632	(40.3)	792	(36.3)
High	5779	(25.0)	7379	(21.8)	556	(25.5)
Missing	55	(0.2)	943	(2.8)	42	(1.9)
<b>Country of origin</b>						
Sweden	22674	(98.2)	33326	(98.6)	2154	(98.6)
Other Scandinavian countries	223	(1.0)	250	(0.7)	15	(0.7)
Europe	140	(0.6)	139	(0.4)	13	(0.6)
Other	42	(0.2)	50	(0.1)	2	(0.1)
Missing	0	(0.0)	40	(0.1)	0	(0.0)
<b>Charlson comorbidity index (3-4)</b>						
0	17700	(76.7)	27040	(80.0)	1759	(80.5)
1	3201	(13.9)	4113	(12.2)	278	(12.7)
2	1428	(6.2)	1648	(4.9)	96	(4.4)
3+	750	(3.2)	1004	(3.0)	51	(2.3)

<sup>1</sup> Prior to 2000 Gleason scoring was based on the WHO classification system (5).



**Table 7** Publications based on data in the National Prostate Cancer Register (NPCR) of Sweden

First author	Journal	Publication Year	Topic	Finding
Ladjevardi (6)	Eur Urol	2010	Tumour grade, treatment and relative survival	Men with well-differentiated PCa have a survival close to the general population whereas men with poorly differentiated PCa have a much worse outcome
Stattin (7)	JNCI	2010	Outcomes in men with localized PCa	10 year PCa-mortality was 3.6% in surveillance group and 2.7% in curative group curatively
Holmström (8)	J Urol	2010	Outcome after primary and deferred treatment after initial surveillance	No significant difference was noted in terms of 1 or more adverse pathological factors; positive margins, extraprostatic extension or upgrading of Gleason score
Bratt (9)	Scand J Urol Nephrol	2010	Uptake of PSA testing In Sweden	At least one-third of men in Sweden have undergone a PSA test
Carlsson (10)	Scand J Urol Nephrol	2009	Post-operative mortality after radical prostatectomy	4/3700 men ( 0.11%) died within 30 days after radical prostatectomy
Andren(11)	Br J Cancer	2009	PCa mortality in men diagnosed at TUR-P	26% of the men had died of PCa at 10 years after TUR-P
Holmberg (12)	Cancer Causes Control	2009	Variation in prognosis according to date of diagnosis	Men diagnosed with PCa in summer time had a more advanced disease at date of diagnosis likely due to less times for appointments in the summer
Stattin (1)	J Urol	2008	Use of surveillance and deferred treatment in localized PCa in men below 70 years 1997-2002	Surveillance was used in 2,065 men (26%) and 711 of these men (34%) received deferred treatment after a median FU of four years
Sandblom (13)	Cancer	2008	Association between PSA levels and survival	Men with PSA above 4 ng/ml had a linear decrease in survival with increasing PSA. A small group of men with PSA below 4 ng/ml had a very poor outcome
Fall (14)	Scand J Urol Nephrol	2008	Assessment of reliability of death certificates	Overall agreement between Cause of Death Register and chart review was 86%
Adolfsson (15)	Scand J Urol Nephrol	2007	Trends in stage and grade, and patterns of care	Stage migration was prominent and there was large geographical differences
NPCR (16)	-	2006-	Annual report	<a href="http://www.vinkancer.se/sv/INCA/kvalitetsregister/Prostatacancer332/rapporter/">http://www.vinkancer.se/sv/INCA/kvalitetsregister/Prostatacancer332/rapporter/</a>
Aus (17)	Cancer	2005	15 year PCa survival in South-east region	At 15 years of follow-up of men in all stages of PCa 56% had died of Pca
Stattin (18)	Scand J Urol Nephrol	2005	Geographical variation in incidence	There was more than four-fold difference in incidence of small impalpable PCa between counties
Varenhorst (19)	Scand J Urol Nephrol	2005	Trends in incidence and treatment	Incidence increased during the study period and the proportion of men that received curative treatment doubled
Sennfält (20)	Acta Oncol	2004	Health economical analysis PCa	Optimal pain treatment was calculated to add 0.85 quality-adjusted years to a man's life
Sandblom (21)	Br J Cancer	2004	Quality of life in men with advanced PCa	Quality of life declined in men with tumour progression
Stattin (22)	Scand J Urol Nephrol	2003	Use of opportunistic PSA screening in year 2000	One-third of men with impalpable tumours (T1c) had initiated workup because of PSA-testing but no symptoms
Sandblom (23)	Scand J Urol Nephrol	2003	Validity of data in NPCR South-east region	Acceptable reproducibility was found between two independent extractions of data from medical charts
Aus (24)	Eur Urol	2003	Outcome in men with lymph node metastasis (N1) in NPCR South-east region	Median survival for men with N1 disease was eight years
Sandblom (25)	Scand J Urol Nephrol	2002	PSA and stage and grade	Higher PSA was noted in men with advanced PCa and with poorly differentiated PCa
Sandblom (26)	Scand J Urol Nephrol	2002	Bone scans and PSA	For men with PSA below 20 ng/ml and well or intermediately differentiated PCa bone scan can be omitted as there is a very low risk of bone metastases
Sandblom (27)	Br J Cancer	2001	Assessment of quality of life	Pain treatment is essential for quality of life
Sandblom (28)	Cancer	2000	Trends in incidence and treatment in NPCR South-east region	Use of GnRH analogues increased 10-fold between 1986 and 1996
Sandblom (29)	Scand J Urol Nephrol	1999	Comparison of incidence in four regions in NPCR	Large variations in incidence were noted

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**Questionnaire:** Questionnaire with Patient Reported Outcome Measures (PROM) to assess patient outcomes such as urinary incontinence and erectile dysfunction.

**Answer the questions by ticking the most appropriate level.**

1. Does your prostate cancer or the treatment limit your daily activities?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
2. Do you have problems with your urinary tract?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
3. Do you have a weak urine stream?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
4. Do you have any leakage of urine on exertion?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
5. Do you ever have to rush to the toilet to pass urine?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
6. Do you have leakage of urine connected to urgency?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
7. How much do your urinary problems influence your daily activities?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
8. On which occasion(s) do you have leakage of urine?  
 No leakage at all  
 Coughing, sneezing or laughing  
 Heavy lifting  
 When you stand up from a sitting position  
 Walking on the flat  
 Without exertion (always)  
 Other reason Which? .....
9. Do you use any protection for urine leakage (pads)?  
 No  
 Yes, Pads Amount/day.....  
 How often?  
 Whenever out of the house  
 During the day  
 During the night  
 Other occasion.....
10. How would you feel if you lived the rest of your life with your urinary problems as they are now?  
 Very content  
 Content  
 Satisfactory  
 Mixed feelings  
 Displeased  
 Unhappy  
 Terrible
11. Do you have a problem with your bowel movements?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
12. Do you have to rush to the toilet in the morning because of bowel movements?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much
13. Do you have any leakage of stools?  
 No  1  2  3  4  5  6  7  8  9  10  Very Much

**Answer the questions by ticking the most appropriate level.**

14. Do you have mucus in your stools?  
No            Very Much
15. Do you have blood in your stools?  
No            Very Much
16. How much influence do your bowel problems have on your daily life?  
No            Very Much
17. On which occasion(s) do you have leakage of stools?  
 No leakage at all  
 Coughing, sneezing or laughing  
 Heavy lifting  
 When standing up from a sitting position  
 When passing gas  
 Other occasion Which? .....
18. How would you feel if you lived the rest of your life with your bowel problems as they are now?  
 Very content  
 Content  
 Satisfactory  
 Mixed feelings  
 Displeased  
 Unhappy  
 Terrible
19. Do you have a partner (wife, partner who lives with you, companion)?  
 Yes  
 No
20. Do you have a problem with your sex life?
21. Have you used assistance to carry out sexual intercourse?  
 No, Go to question Nr 23  
 Yes, Aprostadil How often?  
 Yes, Bondil  Always  
 Yes, Viagra  Seldom  
 Yes, Other .....  Never
22. Is the erection sufficient WITH assistance (see question no 21) to carry out sexual intercourse?  
 Yes  
 No
23. Is the erection sufficient WITHOUT assistance (see question no 21) to carry out sexual intercourse?  
 Yes  
 No



**Answer the questions by ticking the most appropriate level.**

32. During the past 1-2 months, how often have you got up to urinate during a typical night?	<input type="checkbox"/> Never	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times	<input type="checkbox"/> Four times	<input type="checkbox"/> Five times or more
33. Do you have urinary leakage?	<input type="checkbox"/> Never	<input type="checkbox"/> Leakage sometimes while coughing or sneezing, or use of pads during physical activity, eg sporting activity, working in the garden		<input type="checkbox"/> Always use pads (probably during night) but they are not always wet	<input type="checkbox"/> Always use pads which have to be changed because they are wet	<input type="checkbox"/> Continuous leakage and use of pads which have be changed continuously
34. If you are sexually active, how often have you reached orgasm?	<input type="checkbox"/> Never	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Half of the occasions	<input type="checkbox"/> More than half of the occasions	<input type="checkbox"/> Always or almost always	

Answer the questions by ticking the most suitable level if your situation is **WITHOUT** assistance (see question no 21). Answer only one alternative for each question.

35. During the last 6 months, how do you rate your confidence that you could get and keep an erection?	<input type="checkbox"/> Very low or none	<input type="checkbox"/> Low	<input type="checkbox"/> Moderate	<input type="checkbox"/> High	<input type="checkbox"/> Very high	
36. During the past 6 months, when you had erections with sexual stimulation, how often were your erections hard enough for penetration?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Never or almost never	<input type="checkbox"/> A few times (less than half of the attempts)	<input type="checkbox"/> Sometimes (approximately half of the attempts)	<input type="checkbox"/> Most times (more than half of the attempts)	<input type="checkbox"/> Always or almost always
37. During the past 6 months, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Never or almost never	<input type="checkbox"/> A few times (less than half of the attempts)	<input type="checkbox"/> Sometimes (approximately half of the attempts)	<input type="checkbox"/> Most times (more than half of the attempts)	<input type="checkbox"/> Always or almost always
38. During the past 6 months, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Extremely difficult	<input type="checkbox"/> Very difficult	<input type="checkbox"/> Difficult	<input type="checkbox"/> Slightly difficult	<input type="checkbox"/> Not difficult
SATISFACTION 39. During the past 6 months, when you attempted sexual intercourse, how often was it satisfactory for you?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Never or almost never	<input type="checkbox"/> A few times (less than half of the attempts)	<input type="checkbox"/> Sometimes (approximately half of the attempts)	<input type="checkbox"/> Most times (more than half of the attempts)	<input type="checkbox"/> Always or almost always

### Answer the questions by ticking the most suitable level

Answer the questions by ticking the most suitable level if your situation is **WITH** assistance (see question no 21).  
Answer only one alternative for each question.

40. During the last 6 months, how do you rate your confidence that you could get and keep an erection?	<input type="checkbox"/> Very low or none	<input type="checkbox"/> Low	<input type="checkbox"/> Moderate	<input type="checkbox"/> High	<input type="checkbox"/> Very high	
41. During the past 6 months, when you had erections with sexual stimulation, how often were your erections hard enough for penetration?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Never or almost never	<input type="checkbox"/> A few times (less than half of the attempts)	<input type="checkbox"/> Sometimes (approximately half of the attempts)	<input type="checkbox"/> Most times (more than half of the attempts)	<input type="checkbox"/> Always or almost always
42. During the past 6 months, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Never or almost never	<input type="checkbox"/> A few times (less than half of the attempts)	<input type="checkbox"/> Sometimes (approximately half of the attempts)	<input type="checkbox"/> Most times (more than half of the attempts)	<input type="checkbox"/> Always or almost always
43. During the past 6 months, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Extremely difficult	<input type="checkbox"/> Very difficult	<input type="checkbox"/> Difficult	<input type="checkbox"/> Slightly difficult	<input type="checkbox"/> Not difficult
SATISFACTION 44. During the past 6 months, when you attempted sexual intercourse, how often was it satisfactory for you?	<input type="checkbox"/> I am currently not sexually active	<input type="checkbox"/> Never or almost never	<input type="checkbox"/> A few times (less than half of the attempts)	<input type="checkbox"/> Sometimes (approximately half of the attempts)	<input type="checkbox"/> Most times (more than half of the attempts)	<input type="checkbox"/> Always or almost always

***Thank you for your help!***