

Online supplementary table 1. Registered variables in the tumour characteristics at diagnosis form in the Swedish National Register of Urinary Bladder Cancer (SNRUBC) and their capture ratios. Capture ratios was calculated annually according to year of diagnosis.

Variable	Options	Available years	Mean capture ratio	Capture ratio 2014
Code for the reporting hospital or clinic		1997-	100%	100%
Department code		1997-	100%	100%
Reporting date		1997-	100%	100%
T stage	Tis, Ta, T1, T2a, T2b, T3a, T3b, T4a, T4b, Tx, T0 (Tis, Ta, T1, T2, T3, T4, Tx**)	1997-	100%	100%
N stage	N0, N1, N2, N3, Nx (N0, N+, Nx**)	1997-	99%	100%
M stage	M0, M1, Mx	1997-	99%	100%
Clinical date of diagnosis*		1997-	100%	100%
Age at diagnosis		1997-	100%	100%
Grade (WHO 1999)	G1, G2, G3, Gx	1997-	98%	97%
Date of received referral		2000-	88%	99%
Reason for referral	Available alternatives: Registered referral	2000-	90%	100%
	Patient contacted specialist unit direct without referral			
Date of referral		2008-	97%	99%
Date of first visit to specialist		2008-	99%	99%
ICD code		2008-	89%	57%
Morphology code (SNOMED)		2008-	87%	56%
Date of TUR/px		2008-	99%	100%
Morphological confirmation of diagnosis	Available alternatives: Cytology PAD/Biopsy	2008-	100%	100%
Maximal tumour diameter (mm)		2012-	95%	100%
Number of tumours	1,2,3,4,5,6-10,10+	2012-	66%	74%
Carcinoma in situ	Yes/No	2012-	92%	96%

The first year of nationwide capture ratio >50% was set as start year for each separate variable.

*Used as reference

**Categories available in before 2007

Online supplementary table 2. Registered variables in the treatment form in the Swedish National Register of Urinary Bladder Cancer (SNRUBC) and their capture ratios. Capture ratios was calculated annually according to year of diagnosis.

Variable	Options	Available years	Mean capture ratio	Capture ratio 2014
Code for the reporting hospital or clinic		1997-	100%	100%
Department code		1997-	100%	100%
Reporting date*		1997-	100%	100%
Discussed at multidisciplinary conference	Yes/no	2008-	100%	100%
Single dose chemotherapy	Yes/no	2008-	100%	100%
Re-resection	Yes/no	2008-	100%	100%
Additional treatment	Yes/no	1997-	100%	100%
Intravesical treatment**	Yes/no	1997-	100%	99%
Date of commencing intravesical instillations		2004-	95%	100%
Type of intravesical treatment	Available alternatives:	2008-	100%	100%
	BCG			
	chemotherapy (multiple courses)			
Systemic chemotherapy**', ***	Yes/no	1997-	100%	100%
Neoadjuvant chemotherapy**	Yes/no	1999-	80%	100%
Date of commencing neoadjuvant chemotherapy**		2008-	99%	99%
Adjuvant chemotherapy**	Yes/no	1999-	79%	97%
Date of adjuvant chemotherapy**		2008-	99%	100%
Radical cystectomy**', ***	Yes/no	1997-	100%	100%
Date of radical cystectomy**		2003-	95%	99%
Urinary diversion**	Available alternatives:	1997-	98%	97%
	Neobladder			
	Continent cutaneous diversion			
	Ileal conduit			
Type of lymphadenectomy**	Available alternatives:	2008-	96%	91%
	None			
	Obturator fossa			
	Iliac bifurcation			
	Aortic bifurcation			
Treating hospital code for cystectomy**		2008-	98%	98%
Curative external beam radiation**', ****	Yes/no	1997-	100%	100%
Date of commencing curative external beam radiation**		2003-	91%	98%
Treating hospital code curative radiation**		2008-	99%	98%

The first year of nationwide capture ratio >50% was set as start year for each separate variable.

* Year of diagnosis in combination with a non-missing value of reporting date of treatment form has been used as reference.

**Variable registered if yes chosen as option chosen in previous variable.

***From 2008, variable registered if no chosen as option in previous variable (intravesical treatment)

**** From 2008, variable registered if no chosen as option in previous variables (intravesical treatment and cystectomy)

Online supplementary table 3 Registered variables in the five-year follow-up form in the Swedish National Register of Urinary Bladder Cancer (SNRUBC) and their capture ratio. Data available from 2009, and for participants with non-muscle invasive bladder cancer (stage Ta, Tis or T1) without metastases at diagnosis, with date of diagnosis in 2004, and thereafter.

Variable	Options	Mean capture ratio	Capture ratio 2014
Code for the reporting hospital or clinic		100%	100%
Department code		100%	100%
Reporting date *		100%	100%
Recurrence	Yes/no	82%	78%
Date of recurrence**		100%	100%
Progression	Yes/no	74%	76%
Date of progression**		97%	97%
Missing follow up***	Reason of missing follow up (Free text)	NA	NA

*Used as reference

**Variable only registered if yes chosen as option chosen in previous variable.

*** Checkbox only for participants with missing follow-up

Online supplementary table 4 Registered variables in cystectomy form in the Swedish National Register of Urinary Bladder Cancer (SNRUBC) and their capture ratios. Data available from participants with radical cystectomy performed in 2011, and thereafter.

Variable	Options	Mean capture ratio	Capture ratio 2014
Code for the reporting hospital or clinic		100%	100%
Department code		100%	100%
Reporting date		100%	100%
PREOPERATIVE DATA			
Weight	Kg	99%	100%
Height	Cm	99%	100%
BMI	Kg/m ²	98%	99%
American Society of Anesthesiologists (ASA) score	Numerical values from 1 to 6	99%	99%
Previous pelvic surgery or radiation	Yes/no	99%	99%
Clinical T stage	Tis, Ta, T1, T2a, T2b, T3a, T3b, T4a, T4b, Tx, T0	100%	100%
Clinical N-stage	N0, N1, N2, N3, Nx	100%	100%
Clinical M-stage	M0, M1, Mx	100%	100%
Neoadjuvant chemotherapy	Yes/no	99%	100%
PERIOPERATIVE DATA			
Code for hospital performed radical cystectomy		98%	100%
Date of radical cystectomy*		100%	100%
Type of surgery	Available alternatives:	100%	100%
	Open		
	Laparoscopy		
	Robot		
Type of lymphadenectomy	Available alternatives:	100%	100%
	None		
	Obturator fossa		
	Iliac bifurcation		
	Aortic bifurcation		
	Only enlarged lymph nodes		
Primary urethrectomy	Yes/no	100%	100%
Type of urinary diversion	Available alternatives:	100%	100%
	Ileal conduit (Bricker)		
	Continent cutaneous diversion		
	Neobladder		
	Other		
Perioperative bloodloss	Number of ml	98%	98%
Perioperative transfusion	Yes/no	95%	95%
Duration of surgery	Number of minutes	98%	97%
Accidental organ injury	Yes/no	100%	100%

POSTOPERATIVE DATA			
Complications at 90 days	Yes/no	99%	99%
Re-operation within 90 days	Yes/no	99%	99%
Length of stay	Number of days	99%	99%
Unscheduled readmission within 90 days	Yes/no	98%	98%
pT stage	Tis, Ta, T1, T2a, T2b, T3a, T3b, T4a, T4b, Tx, T0	99%	99%
Number of excised lymph nodes	Numerical	97%	99%
Number of excised metastatic lymph nodes	Numerical	96%	98%
Death after operation	Yes/no	99%	99%
Cause of death**	Available alternatives:	100%	100%
	Bladder cancer		
	Other		
	Unknown		

*Used as reference

**Variable only registered if yes chosen as option chosen in previous variable.

Online supplementary table 5 Registered data on complications and re-operations recorded within 90 days after radical cystectomy in the Swedish National Register of Urinary Bladder Cancer (SNRUBC). Data available from participants with radical cystectomy performed in 2011, and thereafter.

Gastrointestinal complications (recorded with date, re-operation, and Clavien score)
Postoperative intestinal obstruction
Anastomotic insufficiency
Intestinal fistula
Cardiovascular complications (recorded with date and Clavien score)
Deep vein thrombosis
Pulmonary embolisation
Acute myocardial infarction
Cerebrovascular insult
Arterial thrombosis/emboli
Infectious complications (recorded with date and Clavien score)
Sepsis
Pneumonia
Pyelonephritis
Lymphocele
Other specific infectious complications
Abdominal wall/parastomal complications (recorded with date, re-operation, and Clavien score)
Wound infection
Subcutaneous wound dehiscence
Abdominal wall hernia diagnosed
Parastomal hernia
Other abdominal wall complications
Stoma necrosis
Stoma prolapse
Urinary tract complications (recorded with date, re-operation, and Clavien score)
Ureteroenteric stenosis
Outlet stricture
Other urinary tract complications
Ureteroenteric suture insufficiency
Enterourethral stricture neobladder
Other complications (recorded with Clavien score)

Online supplementary table 6 Proportions of descriptive characteristics of participants registered and lost to follow up in SNRUBC treatment, five year follow-up, and radical cystectomy forms.

	Treatment form		Five year follow up form for non-muscle invasive bladder cancer		Radical cystectomy form*	
	Registered (N=37931)	Lost to follow up (N=727)	Registered (N=8166)	Lost to follow up (N=1155)	Registered (N=1418)	Lost to follow up (N=252)
Gender						
Male	75%	74%	76%	77%	76%	81%
Female	25%	26%	24%	23%	24%	19%
Year of diagnosis						
January 1, 1997 to December 31, 2002	30%	15%	NA	NA	2%	2%
January 1, 2003 to December 31, 2008	32%	66%	89%	35%	6%	6%
January 1, 2009 to December 31, 2014	38%	19%	11%	65%	92%	92%
Age at diagnosis						
Less than 65 years	23%	30%	26%	26%	27%	26%
65 to 69 years	14%	14%	14%	15%	23%	21%
70 to 74 years	17%	15%	15%	16%	24%	24%
75 to 79 years	18%	16%	18%	18%	18%	18%
80 to 84 years	15%	12%	15%	13%	7%	11%
85 years and above	12%	13%	11%	12%	1%	1%
Education level*						
Low	47%	37%	46%	40%	37%	45%
Intermediate	36%	40%	37%	38%	42%	41%
High	17%	23%	18%	22%	21%	14%
Charlson Comorbidity Index prior to diagnosis **						
No comorbidity (0)	59%	60%	59%	58%	70%	68%
Mild comorbidity (1)	17%	16%	17%	18%	14%	12%
Intermediate comorbidity (2)	14%	13%	13%	14%	10%	13%
Severe comorbidity (3 or more)	11%	11%	10%	10%	6%	6%
Health care region						
RCC Stockholm/Gotland	17%	76%	14%	38%	20%	12%
RCC Syd	22%	7%	23%	16%	21%	20%
RCC Sydost	12%	6%	12%	8%	10%	15%
RCC Uppsala/Örebro	21%	7%	22%	14%	22%	13%
RCC Väst	19%	2%	21%	12%	20%	32%
RCC Norr	9%	3%	8%	12%	8%	8%

* Validated compared with the Swedish Patient Register (in-patient register) by the selection of bladder cancer (ICD-10 code C67) and the radical cystectomy (procedure code KCC) or complete pelvic evisceration (procedure code LCE).

** Charlson Comorbidity Index is calculated during a 10-year period prior to diagnosis. Comorbidity scores for metastatic cancer are not included in the Charlson Comorbidity Index for participants with metastatic bladder cancer at date of diagnosis.

Online supplementary table 7 Publications based on the Swedish National Register of Urinary Bladder Cancer (SNRUBC)

Reference	Year	Aim	Conclusion
Thorstenson <i>et al.</i> [1]	2016	To investigate tumour characteristics, treatments, and survival of urinary bladder cancer with respect to gender-related differences.	Female gender had shorter cancer-specific and relative survival, higher rate of aggressive tumours and lower probability of receiving optimal treatment, compared to male gender.
Jahnsen <i>et al.</i> [2]	2015	To investigate temporal trends over 15 years in tumour characteristics, management and survival in bladder cancer	Increasing age of the patients at diagnosis, decreasing proportion of muscle-invasive tumours, more aggressive treatment but no changes in relative survival over time.
Liedberg <i>et al.</i> [3]	2015	To investigate recurrence and progression of non-muscle invasive bladder cancer (NMIBC)	High rate of recurrence and progression, and important disparities in outcome exist between healthcare regions.
Patschan <i>et al.</i> [4]	2015	To investigate the use of Bacillus Calmette–Guérin (BCG) in stage T1 bladder cancer	Intravesical BCG is underused in stage T1 bladder cancer, particularly in patients 75 years or older, and in those treated at low-volume hospitals.
Jerlström <i>et al.</i> [5]	2014	To evaluate complications within 90 days after radical cystectomy.	Higher risk of complications in patients with longer operating time and higher age.
Sabir <i>et al.</i> [6]	2013	To evaluate the impact of hospital volume on local recurrence and distant metastasis after radical cystectomy	Local tumour recurrence after cystectomy was common and more frequent at low volume hospitals than high volume hospitals. Furthermore, overall survival was better at high volume hospitals.
Liedberg <i>et al.</i> [7]	2012	To evaluate complications and reoperations after radical cystectomy for primary bladder cancer	Radical cystectomy was associated with a reoperation rate of 24%, with higher rates in patients receiving a continent cutaneous diversion or bladder substitution.
Jahnsen <i>et al.</i> [8]	2010	To investigate the type of urinary diversion performed after radical cystectomy in	Continent reconstruction after cystectomy for MIBC is performed more often in

		patients with muscle-invasive bladder cancer (MIBC) in Sweden	some healthcare regions and in patients at university hospitals than in county hospitals.
Jahnsen <i>et al.</i> [9]	2009	To investigate the role of curative therapy of muscle-invasive bladder cancer (MIBC) in relation to patient, tumour and hospital characteristics.	Lower rates of curative-intent treatment were found in patients registered at low-volume than at high-volume facilities, and the same was seen when comparing females with males, and patients aged 76 to 80 years with younger patients.
Gårdmark <i>et al.</i> [10]	2006	To analyse the management and outcome of patients with Ta T1 urinary bladder cancer	There are regional variations in the treatment of bladder cancer. A large group of patients, even those at high risk, were undertreated.
Mikulowski <i>et al.</i> [11]	2005	To record the occurrence T1 G1 urinary bladder cancer to the SNRUBC, in order to validate the data on T1 tumours	The re-evaluation of 98 cases found no G1 urothelial carcinoma with infiltrative growth.

References

1. Thorstenson A, Hagberg O, Ljungberg B, et al. Gender-related differences in urothelial carcinoma of the bladder: a population-based study from the Swedish National Registry of Urinary Bladder Cancer. *Scand J Urol* 2016; 1-6.399999
2. Jahnson S, Hosseini Aliabad A, Holmang S, et al. Swedish National Registry of Urinary Bladder Cancer: No difference in relative survival over time despite more aggressive treatment. *Scand J Urol* 2015 Sep 18;50: 14-20.
3. Liedberg F, Hagberg O, Holmang S, et al. Local recurrence and progression of non-muscle-invasive bladder cancer in Sweden: a population-based follow-up study. *Scand J Urol* 2015;49(4): 290-5.
4. Patschan O, Holmang S, Hosseini A, et al. Use of bacillus Calmette-Guerin in stage T1 bladder cancer: Long-term observation of a population-based cohort. *Scand J Urol* 2015;49(2): 127-32.
5. Jerlstrom T, Gardmark T, Carringer M, et al. Urinary bladder cancer treated with radical cystectomy: Perioperative parameters and early complications prospectively registered in a national population-based database. *Scand J Urol* 2014;48(4): 334-40.
6. Sabir EF, Holmang S, Liedberg F, et al. Impact of hospital volume on local recurrence and distant metastasis in bladder cancer patients treated with radical cystectomy in Sweden. *Scand J Urol* 2013;47(6): 483-90.
7. Liedberg F, Holmberg E, Holmang S, et al. Long-term follow-up after radical cystectomy with emphasis on complications and reoperations: a Swedish population-based survey. *Scand J Urol Nephrol* 2012;46(1): 14-8.
8. Jahnson S, Damm O, Hellsten S, et al. Urinary diversion after cystectomy for bladder cancer: a population-based study in Sweden. *Scand J Urol Nephrol* 2010;44(2): 69-75.
9. Jahnson S, Damm O, Hellsten S, et al. A population-based study of patterns of care for muscle-invasive bladder cancer in Sweden. *Scand J Urol Nephrol* 2009;43(4): 271-6.
10. Gardmark T, Bladstrom A, Hellsten S, Malmstrom PU. Analysis of clinical characteristics, management and survival of patients with Ta T1 bladder tumours in Sweden between 1997 and 2001. *Scand J Urol Nephrol* 2006;40(4): 276-82.
11. Mikulowski P, Hellsten S. T1 G1 urinary bladder carcinoma: Fact or fiction? *Scand J Urol Nephrol* 2005;39(2): 135-7.