

BMJ Open Cohort profile: Bladder Cancer Data Base Sweden (BladderBaSe) 2.0

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To cite: Häggström C, Hagberg O, Gårdmark T, *et al.* Cohort profile: Bladder Cancer Data Base Sweden (BladderBaSe) 2.0. *BMJ Open* 2022;**12**:e064898. doi:10.1136/bmjopen-2022-064898

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-064898>).

Received 17 May 2022

Accepted 01 December 2022

ABSTRACT

Purpose We constructed Bladder Cancer Data Base Sweden (BladderBaSe) 2.0 to expand studies in BladderBaSe on incidence, treatment outcomes, side effects, survival and health economic aspects of men and women with cancer in the urinary bladder, upper tract urothelial carcinoma (UTUC) (renal pelvis and ureter) and urethral carcinoma.

Participants BladderBaSe 2.0 includes 53 298 patients with cancer in the urinary bladder, diagnosed from 1 January 1997 to 31 December 2019, and 961 patients with UTUC in the renal pelvis and 792 in the ureter, and 146 patients with urethral urothelial carcinoma, diagnosed from 1 January 2015 to 31 December 2019, and in total 275 816 participants in reference groups, free of cancer in the urinary tract, matched 1:5 on sex, age and county.

Findings to date To date, 18 published studies based on data from the BladderBaSe have investigated calendar time trends in survival; impact of gender, socioeconomic factors, tumour aggressiveness and hospital volume for radical cystectomy on prognosis; survival after radical cystectomy compared with radical radiotherapy; risk factors for complications and side effects after radical cystectomy such as thromboembolism, strictures of ureteroenterostomies and incisional hernia.

Future plans The BladderBaSe initiators are currently investigating gender-dependent detection delays due to urinary tract infections; survival after non-muscle invasive bladder cancer with respect to the number of transurethral resections; short-term outcomes comparing open and robot-assisted radical cystectomy; studies on risk for intravesical recurrence after different diagnostic measures in UTUC, and suicide risk after bladder cancer diagnosis. The BladderBaSe project group is open for collaborations with national and international colleagues.

INTRODUCTION

We have previously linked data from The Swedish National Register for Urinary Bladder Cancer (SNRUBC) to several national health-care and demographic registers to construct the Bladder Cancer Data Base Sweden (BladderBaSe).¹ The linkage created a comprehensive and population-based cohort of patients with bladder cancer with detailed data on background and tumour characteristics, treatment, socioeconomic factors,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The Bladder Cancer Data Base Sweden (BladderBaSe) 2.0 includes data from 55 197 patients with cancers in the urinary tract, using national registers with high coverage collected during more than 20 years.
- ⇒ The BladderBaSe 2.0 includes information on tumour characteristics and treatments, extensive follow-up through registers, and data on important confounding factors such as socioeconomic variables and comorbidity.
- ⇒ The BladderBaSe 2.0 includes data of 275 816 randomly selected matched reference participants to the cancer cases.
- ⇒ Results from specific validation studies are included as attachments.
- ⇒ Limitations are lack of lifestyle data such as smoking and alcohol use, and molecular information of the cancer cases.

comorbidity and causes of death enabling studies of incidence trends, effects of treatment, overall and disease-specific survival.

For further studies of the epidemiology, care, management and outcomes for patients with cancer in the urinary tract, we constructed the BladderBaSe 2.0. This novel research database expands the previous version to also include: (1) longer follow-up, with data additional from patients diagnosed through 2019 and updated data in the SNRUBC (described below in further detail); (2) patients with urothelial carcinoma of the upper urinary tract (UTUC) (renal pelvis and ureter) and urethra; (3) data from the Prescribed Drug Register; (4) reference populations free of cancer in the urinary tract, randomly selected from the background population and individually matched on age, sex and county, at the date of diagnosis of the patients. The matched participants can be used as a prospective comparison cohort or as controls in case-control designs.



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COHORT DESCRIPTION

The Swedish National Register for Urinary Bladder Cancer (SNRUBC)

The BladderBaSe 2.0 like the previous version builds on SNRUBC¹ with its current updates. SNRUBC is a clinical database created for clinical audit and research. Data in the SNRUBC are updated with half-year intervals and presented in an interactive online report.² All new diagnoses of a tumour in the urinary tract for individuals 18 years or older are requested to be reported into the SNRUBC. The specific coding criteria for inclusion are shown in online supplemental table 1. The records in SNRUBC are validated and checked for completeness by comparison with the Swedish Cancer Register, to which reporting is mandated by law (see below). The total capture ratio as compared with the Swedish Cancer Registry was 2017–2019 between 97% and 99%. For the same years, the capture ratios stratified by cancer sites were >98%, for cancer in the urinary bladder and UTUC, and around 90% for urethral carcinoma.²

Patient records in the SNRUBC are standardised into different registration forms. For bladder cancer, five different forms are used and for UTUC and urethral carcinoma, three different forms are used, with separate variables adapted for each cancer site. An overview of the different forms and their included variables is shown in [table 1](#). For bladder cancer, the forms for tumour information at diagnosis and primary treatment have been used since the initiation of the SNRUBC, 1 January 1997. Participants with non-muscle invasive bladder cancer (NMIBC) (stage Ta, Tis or T1) without metastases diagnosed 2004 and onwards are followed up at 5 years after diagnosis for relapse, progression, and death. From 1 January 2011, detailed data in conjunction with radical cystectomy are registered including surgical parameters, complications and reoperations up to 90 days postoperatively.

Updates in SNRUBC included in BladderBaSe 2.0 are data on UTUC and urethral carcinomas since 1 January 2015, including forms for tumour information at diagnosis and primary treatment. From 1 January 2017, oncological treatments are reported with details on neoadjuvant, adjuvant, induction or palliative systemic treatment for all patients with any urinary tract cancer. Sequential reporting of oncological systemic treatments for locally advanced and/or metastatic disease can also be reported in the SNRUBC.

Flow chart and number of participants included in each registration form are shown in [figure 1](#) for bladder cancer, and in online supplemental figure 1 for patients with (A) UTUC in the renal pelvis and ureter, and (B) urethral carcinoma. The variables and different options included in the forms for diagnosis of bladder cancer, primary treatment, radical cystectomy and 5-year follow-up for NMIBC and their capture ratios are shown in [tables 2–5](#). Detailed data of complications and reoperations registered in the radical cystectomy form is listed

in online supplemental table 2. Variables and options for diagnosis and primary treatment for UTUC in the renal pelvis and ureter, and for urethral carcinoma are shown in online supplemental tables 3–5. Capture ratios for the four different parts of the oncological treatment form for all cancer sites included are shown in online supplemental table 6. Detailed data on neoadjuvant, induction, adjuvant and palliative systemic oncological treatment is listed in online supplemental table 7.

The BladderBaSe 2.0

In 2020, data on participants in the SNRUBC with date of diagnosis from 1 January 1997 to 31 December 2019, were linked to a number of healthcare and demographic registries at the National Board of Health and Welfare and the Statistics Sweden by use of the personal identification number (PIN)³ (see [figure 2](#)). A matched reference group with individuals free from cancer in the urinary tract at the time of diagnosis of the index case were randomly selected from the background population at Statistics Sweden. Five reference participants were selected without replacement for each index cancer patient at date of diagnosis, matched for sex, year of birth and county, separately for each cancer site in the urinary tract. The referent participants were allowed to later develop cancer in the urinary tract; hence one individual could first be a referent in the database and later a patient, with corresponding new referents allocated.

Selected data from the Swedish Household Census and the Register of Total Population and Population Changes, and the Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA) were also linked to the data in SNRUBC and the reference population. Data for all individuals (participants in the SNRUBC and the reference population) was linked at the National Board of Health and Welfare to the Cancer Register, The Patient Register, The Cause of Death Register and The Prescribed Drug Register. Participants in the BladderBaSe 2.0 have been assigned an internal identification number, for which the key between the PIN and internal id number is kept exclusively by Statistics Sweden. An overview of variables retrieved from each register is shown in [table 6](#). More details of each register and selected variables are described below. The BladderBase 2.0 is structured as four different study databases, one for each cancer site included.

The Prescribed Drug Register

The Swedish Prescribed Drug Register started in July 2005, and includes all prescribed drugs dispensed at pharmacies.⁴ Each row in the register corresponds to one dispensation at a pharmacy with dose and Anatomical Therapeutic Chemical code. Data on drugs for hormonal treatment, antibiotics, osteoporosis treatment, psychiatric drugs, tuberculosis and cancer treatment, and data on all medications to calculate the Drug Comorbidity Index⁵ were retrieved from this register. The Drug Comorbidity

Table 1 Standardised forms with data collection in the SNRUBC for BladderBaSe 2.0

Cancer types	Registration forms with data collection in SNRUBC (registration years)	Data recorded
Urinary bladder cancer	(1) Characteristics of the primary tumour at diagnosis (1997–2019)	Reporter information: Hospital and department Patient information: Age, sex, smoking status (from 2019), care chain alternative. Dates of: diagnosis, referral, received referral, first visit to specialist and date of TUR/px Tumour information: Cancer site diagnosis, basis of diagnosis suspicion, ICD code, TNM stage, grade, tumour diameter, no of tumours, histology and morphological codes Alternatives for referral reason, basis of diagnosis suspicion, morphological confirmation
	(2) Primary treatment (1997–2019)	Reporter information: Hospital and department Primary investigation options: discussed on multidisciplinary tumour board, single dose chemotherapy, reresection, grade, T stage Date and hospital details of given treatment: Intravesical instillations, systemic oncological treatment (neoadjuvant, adjuvant, palliative), partial cystectomy, radical cystectomy or curative radiotherapy.
	(3) Follow-up at 5 years after diagnosis for non-muscle invasive bladder cancer (2009–2019)	Reporter information: Hospital and department Status of recurrence and progression.
	(4) Preoperative, perioperative and postoperative events in conjunction with radical cystectomy (2011–2019)	Reporter information: Hospital and department Preoperative data: TNM stage, weight, height, body mass index, American Society of Anesthesiologists score, Charlson Comorbidity Index, previous pelvic surgery, radiation, or neoadjuvant chemotherapy Perioperative data: Type of surgery, type of lymphadenectomy, type of urinary diversion, blood loss, duration of surgery, accidental organ injury during surgery Postoperative data: Complications, reoperations and readmissions within 90 days, length of hospital stay, pT stage, no of excised lymph-nodes and number of excised and metastatic lymphnodes
	(5) Oncological treatment (2017–2019)	Reporter information: Hospital and department Treatment details of: Treatment intention for systemic therapy (neoadjuvant, adjuvant, induction, palliative), Eastern Cooperative Oncology Group (ECOG) Performance status score, distribution of metastases (date and locations), systemic antitumoural treatment regimen, number of cycles, treatment response, rechallenge, side effects, line of palliative treatment and reason for ending treatment.
Upper tract urothelial carcinoma (UTUC) in the renal pelvis	(1) Characteristics of the primary tumour at diagnosis (2015–2019)	Reporter information: Hospital and department Patient information: age, sex, smoking status (from 2019), standardised care pathway referral Dates of: diagnosis, referral, received referral and first visit to specialist Tumour information: Cancer site diagnosis, basis of diagnosis suspicion, International Classification of Diseases (ICD) code, TNM stage, grade, histology and morphological codes Side (right/left) Previous urothelial carcinoma elsewhere in the urinary tract
	(2) Primary treatment (2015–2019)	Reporter information: Hospital and department Primary investigation options: Discussed on multidisciplinary tumour board, single dose chemotherapy, grade, TNM stage Date of treatment decision Date and hospital details of given treatment: Nephroureterectomy, bladder cuff included in the specimen, nephrectomy, local resection, endoluminal resection/coagulation, endoluminal instillation of BCG/chemotherapy and curative treatment.
	(3) Oncological treatment (2017–2019)	Reporter information: Hospital and department Treatment details of: Treatment intention for systemic therapy (neoadjuvant, adjuvant, induction, palliative), ECOG Performance status score, distribution of metastases (date and locations), systemic antitumoural treatment regimen, number of cycles, treatment response, rechallenge, side effects, line of palliative treatment and reason for ending treatment.

Continued

**Table 1** Continued

Cancer types	Registration forms with data collection in SNRUBC (registration years)	Data recorded
UTUC in the ureter	(1) Characteristics of the primary tumour at diagnosis (2015–2019)	Reporter information: Hospital and department Patient information: Age, sex, smoking status (from 2019), standardised care pathway referral Dates of: diagnosis, referral, received referral and first visit to specialist Tumour information: Cancer site diagnosis, basis of diagnosis suspicion, ICD code, TNM stage, grade, histology and morphological codes Side (right/left) Previous urothelial carcinoma elsewhere in the urinary tract
	(2) Primary treatment (2015–2019)	Reporter information: Hospital and department Primary investigation options: Discussed on multidisciplinary tumour board, local resection, grade, TNM stage, tumour discovered at cystectomy Date of treatment decision Date and hospital details of given treatment: Nephroureterectomy, bladder cuff included in the specimen, nephrectomy, systemic chemotherapy (neoadjuvant/induction/adjuvant or palliative intent), local resection, endoluminal resection/coagulation, endoluminal instillation of BCG/chemotherapy and curative treatment.
	(3) Oncological treatment (2017–2019)	Reporter information: Hospital and department Treatment details of: Treatment intention for systemic therapy (neoadjuvant, adjuvant, induction, palliative), ECOG Performance status score, distribution of metastases (date and locations), systemic antitumoural treatment regimen, no of cycles, treatment response, rechallenge, side effects, line of palliative treatment and reason for ending treatment.
Urethral carcinoma	(1) Characteristics of the primary tumour at diagnosis (2015–2019)	Reporter information: Hospital and department Patient information: Age, sex, smoking status (from 2019), standardised care pathway referral Dates of: diagnosis, referral, received referral and first visit to specialist Tumour information: Cancer site diagnosis, basis of diagnosis suspicion, ICD code, TNM stage, grade, histology and morphological codes Previous urothelial carcinoma elsewhere in the urinary tract
	(2) Primary treatment (2015–2019)	Reporter information: Hospital and department Primary investigation options: Discussed on multidisciplinary tumour board, local resection, grade, TNM stage, tumour discovered at cystectomy Date of treatment decision Date and hospital details of given treatment: Cystoprostatourethrectomy/cysturethrectomy, systemic chemotherapy (neoadjuvant/induction/adjuvant or palliative intent), urethrectomy/local resection, endoluminal resection/coagulation, endoluminal instillation BCG/chemotherapy and curative treatment.
	(3) Oncological treatment (2017–2019)	Reporter information: Hospital and department Treatment details of: Treatment intention for systemic therapy (neoadjuvant, adjuvant, induction, palliative), ECOG Performance status score, distribution of metastases (date and locations), systemic antitumoural treatment regimen, no of cycles, treatment response, rechallenge, side effects, line of palliative treatment and reason for ending treatment.

BladderBaSe, Bladder Cancer Data Base Sweden; SNRUBC, Swedish National Register for Urinary Bladder Cancer; TUR, transurethral resection.

Index is built of data of prescribed drugs within 1-year period before diagnosis/index date for cases/referents.

The Patient Register

The Swedish Patient Register includes information regarding inpatient and outpatient care from 1987. The Charlson Comorbidity Index (CCI) was calculated with data from the Patient Register to estimate the concomitant disease burden of the both the cases and the reference population in BladderBaSe 2.0.⁶ The CCI was calculated based on recorded diagnoses withing 10 years prior to diagnosis/

index date for cases/referents. A validation study of the Patient Register reported high validity for most diagnoses, with a positive predictive value about 85%–95%.⁷ Furthermore, data were retrieved both prior to and after the date of bladder cancer diagnosis from the Patient Register on risk factors for bladder cancer, risk factors of treatment side effects and/or modifiers of treatment response and natural history of the disease. Examples of such data are urinary tract infections, diabetes mellitus, chronic obstructive pulmonary disease and abdominal or pelvic surgery.

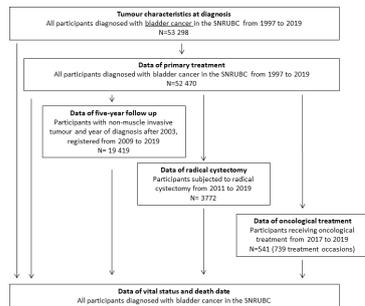


Figure 1 Flow chart and number of participants with bladder cancer included in the different forms of SNRUBC and included in the BladderBaSe 2.0. BladderBaSe, Bladder Cancer Data Base Sweden; SNRUBC, Swedish National Register for Urinary Bladder Cancer.

The Cancer Register

In Sweden, all new histologically, cytologically or clinically diagnosed tumours are by law reported to the Regional Cancer Centres, and these regional registries report once a year to the national Swedish Cancer Registry.⁸ The Swedish Cancer Register was initiated 1958 and has due to mandatory reporting high coverage.⁹ We retrieved data on all other cancer diagnoses and their dates from this register, irrespective of date of bladder cancer diagnosis for all participants in the BladderBaSe 2.0.

The Cause of Death Register

From the Cause of Death Register, we retrieved data on underlying and contributing causes of death and dates of death. The Cause of Death Register was initiated on 1953, and proportion of missing death certificates in 2014 was 1%.¹⁰

Swedish Household Census and the Register of Total Population and Population Changes

We retrieved data from the Register of Total Population and Population Changes and the Swedish Household Census on marital status, continent of birth, dates of immigration and emigration.¹¹ Furthermore, we retrieved data from the Swedish Household Census from year 1990 on socioeconomic status based on the Swedish Socio-Economic Index and profession.

Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA)

The LISA database holds annual registers from 1990 of data based on the labour market, educational and social sectors.¹² The LISA database provides information at an individual level, and at a group level such as families, companies and places of employment. From the LISA database we retrieved information about socioeconomic variables such as educational level, annual family and individual income.

Socioeconomic background factors and comorbidity of participants diagnosed with bladder cancer and their reference group are shown in [table 7](#), and similar data for patients with UTUC and urethral carcinoma and their

corresponding reference groups in online supplemental tables 8–10.

Patient and public involvement

Patients' advocates or public representatives were not involved in the design or conduct of studies in BladderBaSe 2.0. The SNRUBC is, like other Swedish National Quality Registers, obliged to inform all patients prior to registration with an option to opt-out. The SNRUBC steering committee have patient representatives from two organisations and the results from research based on the SNRUBC, including the BladderBaSe 2.0, are transferred back to patient advocates and support groups through the quality assurance system at the Regional Cancer Centres.

FINDINGS TO DATE

Published studies

To date, there are 18 published studies based on the BladderBaSe. A number of clinically relevant inferences have emerged: Age-related differences in prognosis in bladder cancer points to age-dependent differences in management and in tumour biology. Findings about risk of recurrence after stage TaG1 bladder cancer and papillary urothelial neoplasm of low malignant potential (PUNLMP) challenge the recently adapted notion that management strategies can be merged into one low-risk group of NMIBC. Treatment for bladder cancer, after or in conjunction with another primary cancer, should not be neglected and carries the same probability of success as treatment in patients with bladder cancer only. Survival after radical cystectomy in Sweden is similar during holiday and non-holiday periods, contradicting indications about season related survival differences in bladder and renal cancer in other studies. A study of possible factors explaining why a lower socioeconomic status (SES) is associated with lower survival in bladder cancer indicate that comorbidity and treatment delay contribute, but optimisation of all aspects of care across SES strata is necessary. A clinical challenge is an increasing proportion of node-positive patients with significant comorbidity, where one additional publication on the natural history of those patients unable to receive curatively intended therapy reported that they frequently are hospitalised during their final year of life and primarily die of bladder cancer. Our data makes a strong case for a randomised study defining the role of second look resection in stage T1 bladder cancer. The cumulative incidence of midline incisional hernia after cystectomy continues to rise over many years and avoiding postoperative wound dehiscence is a critical preventive measure. Ureteroenteric strictures after cystectomy requiring intervention is a larger clinical problem than previously anticipated and continue to be relevant many years after the primary operation. Findings of the association between caseload and outcome after radical cystectomy support centralisation for surgical treatment of bladder cancer. More details of all these studies are shown in [table 8](#).

**Table 2** Variables, their options and proportions, and variable capture ratios in the standardised form for diagnostic variables for bladder cancer of the SNRUBC in the BladderBaSe 2.0

Variable	Options (proportions)	Recorded years: capture ratio
Date of diagnosis	Date	1997–2019: 100%
Reporting date	Date	1997–2019: 100%
County at diagnosis	Stockholm county: 17.7%	1997–2019: 100%
	Västra Götaland county: 16.7%	
	Skåne county: 15.7%	
	Östergötland county: 4.7%	
	Jönköping county: 3.7%	
	Halland county: 3.4%	
	Kalmar county: 3.3%	
	Värmland county: 3.1%	
	Södermanland county: 3.1%	
	Gävleborg county: 3.0%	
Other counties: 25.7%		
Code for reporting hospital	Hospital codes	1997–2019: 99–100%
Healthcare region	Stockholm/Gotland: 18.5%	1997–2019: 100%
	Uppsala/Örebro: 20.9%	
	South-East: 11.6%	
	South: 21.1%	
	West: 18.7%	
	North: 9.2%	
T stage	Ta: 49.5%	1997–2019: 96–99%
	Tis: 2.8%	
	T1: 23.0%	
	T2: 17.8%	
	T3: 4.2%	
	T4: 2.8%	
N stage	N0: 39.5%	1997–2019: 97–100%
	N+: 3.5%	
	NX: 57.1%	
M stage	M0: 45.5%	1997–2019: 92–100%
	M1: 3.3%	
	MX: 51.2%	
Grade (three classes, GX is set to missing)	G1/LMP: 26.1%	1997–2019: 95–98%
	G2: 32.1%	
	G3-G4/anaplastic: 41.7%	
Date of referral	Date	2008–2019: 94–99%
Reason for referral	Registered referral: 77.7%	2000–2019: 56–100%
	Self-referral by patient: 7.7%	
	Other: 14.6%	
Date of referral registered	Date	2000–2002: 54–67%; 2003–2019: 86–99%
Date of first visit to urologist	Date	2008–2019: 97–100%

Continued

Table 2 Continued

Variable	Options (proportions)	Recorded years: capture ratio
Morphology code (SNOMED)	813021: 19.7%	2008–2019: 82–100%
	813022: 18.0%	
	813033: 17.0%	
	812033: 14.5%	
	813023: 5.8%	
	813032: 5.4%	
	812032: 4.9%	
	81203: 3.6%	
	81202: 2.8%	
	812031: 2.3%	
	Other: 6.2%	
Date of TUR/px	Date	2008–2019: 98–100%
Date of TUR/px*	Date	1997–2019: 85–100%
Maximal tumour diameter	0–10 mm: 23.6%	2012: 43%; 2013–2019: 58–73%
	11–30 mm: 43.4%	
	>30mm: 33.0%	
Carcinoma in situ	No: 78.5%	2012–2019: 28–59%
	Yes: 21.5%	

*Enriched with data from the Patient Register for those patients with missing date in the SNRUBC. BladderBaSe, Bladder Cancer Data Base Sweden; SNRUBC, Swedish National Register for Urinary Bladder Cancer; TUR, transurethral resection.

Some of these findings have changed practice for urothelial carcinoma care in Sweden and been incorporated in the Swedish National Guidelines on Urothelial carcinoma.¹³ For example, the regionalisation of the cystectomy care in Sweden during recent years is supported by the identification of an improved overall survival in hospitals in the highest period-specific mean annual hospital cystectomy volume tertile (above 25 cystectomies annually).¹⁴ The risk of venous thromboembolism after treatment for muscle-invasive bladder cancer, particularly after chemotherapy is increased also beyond 30 days, challenging the current recommendation of prolonged low molecular weight heparin for 4 weeks after radical cystectomy.¹⁵ Furthermore, during follow-up of patients with primary bladder cancer and PUNLMP, follow-up cystoscopies beyond 3 years are not recommended any longer in the Swedish national guidelines on urothelial carcinoma based on a lower risk of recurrence compared with TaG1-tumours.¹⁶

Ongoing investigations

The initiators of BladderBaSe are currently investigating survival of NMIBC, gender-dependent detection delays related to urinary tract infections, outcomes after robot-assisted and open radical cystectomy, studies of outcomes after different diagnostic modalities in UTUC, and psychological effects from a bladder cancer diagnosis, such as suicide. Furthermore, planned projects

involve studies of; associations between hormonal pharmacological interventions and incidence and prognosis in bladder cancer; of risk factors for complications after radical cystectomy among women; of treatment patterns and outcomes for patients with UTUC and urethral carcinomas; of health economy studies in patients with advanced bladder cancer; of long-term consequences of urinary diversion on metabolism and bone health; of the association between different approaches to lymph node dissection and prognosis; and of associations between the metabolic syndrome and risk of and prognosis in bladder cancer.

STRENGTHS AND LIMITATIONS

Strengths

To our knowledge, the BladderBaSe 2.0 forms the largest clinical database for cancers in the urinary tract, with data from 55 197 patients and 275 816 randomly selected reference participants. The cancer cases are recruited from an entire nation in a register with very high coverage, collected during more than 20 years. The main strengths of the BladderBaSe 2.0 are detailed information on tumour characteristics and treatments, extensive follow-up through registers for all individuals, data on important confounding factors such as socioeconomic variables and comorbidity, and access to a large

**Table 3** Variables, their options and proportions, and variable capture ratios in the standardised form for primary treatment variables for bladder cancer of the SNRUBC in the BladderBaSe 2.0

Variable	Options (proportions)	Recorded years: capture ratio
Reporting date	Date	1997–2019: 88–100%
Code for reporting hospital	Hospital codes	1997–2019: 100%
Discussed at multidisciplinary conference	No: 64.0%	2008–2019: 99–100%
	Yes: 36.0%	
Single dose chemotherapy	No: 92.8%	2008–2019: 99–100%
	Yes: 7.2%	
Reresection	No: 77.1%	2008–2019: 98–100%
	Yes: 22.9%	
Additional treatment*	No: 63.2%	1997–2019: 99–100%
	Yes: 36.8%	
Intravesical treatment†	No: 47.2%	1997–2019: 100%
	Yes: 52.8%	
Date of commencing intravesical instillations	Date	2004–2019: 79–100%
Type of intravesical treatment	BCG: 77.3%	2008–2019: 99–100%
	Chemotherapy, multiple instillations: 22.7%	
Systemic chemotherapy‡	No: 88.0%	1997–2019: 100%
	Yes: 12.0%	
Neoadjuvant chemotherapy	No: 33.3%	1997–2003: 29–66%; 2004–2019: 77–100%
	Yes: 66.7%	
Date of commencing neoadjuvant chemotherapy	Date	2008–2016: 80–99%
Adjuvant chemotherapy	No: 75.1%	1997–2003: 29–66%; 2004–2019: 77–99%
	Yes: 24.9%	
Date of commencing adjuvant chemotherapy	Date	2008–2015: 96–100%; 2016: 67%
Radical cystectomy‡	No: 68.2%	1997–2019: 100%
	Yes: 31.8%	
Date of radical cystectomy	Date	2003–2016: 70–100%
First date of radical cystectomy‡	Date	1997–2019: 72–100%
Urinary diversion§	Ileal conduit: 78.4%	1997–2016: 83–100%
	Neobladder: 14.5%	
	Continent cutaneous diversion: 7.1%	
Urinary diversion‡	Ileal conduit: 80.3%	1997–2018: 92–100%; 2019: 62%
	Neobladder: 13.5%	
	Continent cutaneous diversion: 6.1%	
Type of lymphadenectomy	Iliac bifurcation: 63.7%	2008–2016: 82–99%
	Aortic bifurcation: 11.7%	
	Obturator fossa: 10.5%	
	None: 14.1%	
Curative external beam radiation†	No: 94.3%	1997–2019: 100%
	Yes: 5.7%	
Date of commencing curative external beam radiation	Date	2003–2019: 79–99%

*Key variable for further primary treatment data.

†Only available options for patients with additional treatment chosen.

‡Enriched with data from the Patient Register for those patients with missing date in the SNRUBC.

§Data available in the primary treatment form until 2016 to avoid double registration, as these data also are collected in the radical cystectomy form.

BladderBaSe, Bladder Cancer Data Base Sweden; SNRUBC, Swedish National Register for Urinary Bladder Cancer.

Table 4 Variables, their options and proportions, and variable capture ratios in the standardised form for preoperative perioperative and postoperative variables radical cystectomy variables for bladder cancer of the SNRUBC in the BladderBaSe 2.0

Variable	Options (proportions)	Recorded years: capture ratio
Date of radical cystectomy	Date	2011–2020: 100%
Code for reporting hospital	Hospital codes	2011–2020: 100%
Reporting date	Date	1997–2019: 100%
Weight (kg)	Mean: 79.8 kg, median: 79	2011–2020: 98–100%
Height (cm)	Mean: 174 cm, median: 175	2011–2020: 98–100%
Body mass index	Mean: 26.2, median: 25.7	2011–2020: 98–100%
American Society of Anesthesiologists score	Mean: 2.23, median: 2	2011–2020: 98–100%
Previous pelvic surgery or radiation	No: 79.6% Yes: 20.4%	2011–2020: 95–100%
Clinical T stage	Ta: 3.2% Tis: 4.7% T1: 19.2% T2: 54.4% T3: 13.2% T4: 5.3%	2011–2020: 98–99%
Clinical N stage	N0/NX: 90.6% N+: 9.4%	2011–2020: 98–100%
Clinical M stage	M0: 96.7% M1: 1.8% MX: 1.5%	2011–2020: 98–100%
Neoadjuvant chemotherapy	No: 66.7% Yes: 33.3%	2011–2020: 99–100%
Code for hospital performed radical cystectomy	Hospital codes	2011–2020: 95–100%
Type of surgery	Open: 69.9% Robot: 30.1%	2011–2020: 100%
Type of lymphadenectomy	None: 11.2% Iliac bifurcation: 60.4% Obturator fossa: 6.5% Aorta bifurcation: 20.2% Only enlarged: 1.7%	2011–2020: 99–100%
Primary urethrectomy	No: 78.9% Yes: 21.1%	2011–2020: 98–100%
Type of urinary diversion	Illeal conduit (Bricker): 88.0% Cutaneous continent diversion: 0.9% Neobladder: 9.5% Other: 1.6%	2011–2020: 100%
Perioperative bloodloss (mL)	Mean: 767, median: 500	2011–2020: 95–100%
No of blood transfusions	Mean: 3.11, median: 0	2014–2020: 88–99%
Duration of surgery (min)	Mean: 341, median: 326	2011–2020: 95–100%
Accidental organ injury	No: 95.8% Yes: 4.2%	2011–2020: 94–100%
Complications at 90 days	No: 48.5% Yes: 51.5%	2011–2020: 77–100%
Reoperation within 90 days	No: 88.7% Yes: 11.3%	2011–2020: 77–99%
Length of stay (no of days)	Mean: 14.5, median: 12	2011–2020: 78–100%

Continued

**Table 4** Continued

Variable	Options (proportions)	Recorded years: capture ratio
Unscheduled readmission within 90 days	No: 71.8% Yes: 28.2%	2011–2020: 70–98%
pT stage	Ta: 4.7% Tis: 13.1% T1: 10.7% T2: 22.8% T3: 34.0% T4: 14.8%	2011–2020: 65–81%
No of excised lymph nodes	Mean: 17.6, median: 15	2011–2020: 78–99%
No of excised metastatic lymph nodes	Mean:0.85, median:0	1997–2019: 75–100%
Death within 90 days	No: 93.8% Yes: 6.2%	2011–2020: 78–99%
Cause of death	Bladder cancer: 53.6% Other: 35.3% Unknown: 11.2%	2011–2020: 95–100%

BladderBaSe, Bladder Cancer Data Base Sweden; SNRUBC, Swedish National Register for Urinary Bladder Cancer.

reference population which can be used as a prospective comparison cohort or as controls in case–control designs. Information about prescribed drugs and hospitalisations can be used to address questions relating to intended treatment outcomes as well as side effects, and to study health economy. Another strength is the recent validation studies described below.

Validation of data for T1 patients in the SNRUBC as compared with medical charts

Specially trained nurses with extensive experience of registration in the SNRUBC and other national urological registries did a second registration using original data in the medical charts for all patients registered in the SNRUBC 2008 and 2009 with clinically stage T1 (cT1) tumours (N=1044).¹⁷ Variables validated were dates of referral to a urologic consultation and transurethral resection of the tumour. In addition, tumour

characteristics such as tumour grade according to WHO 1999 system and clinical TNM category (TNM 2009) were reregistered as was the primary treatment. The validation registration was also completed with information about T category of the second-look resection. Results from this validation are shown in online supplemental file 2.

Validation of short-term outcomes of radical cystectomy in the SNRUBC

Data in the radical cystectomy form in the SNRUBC (variables listed in table 4) was validated using the linked data from the BladderBaSe 2.0. Data on unscheduled readmissions, reoperations, dates and causes of death within 90 days from radical cystectomy was compared with the Patient Register and the Cause of Death Register among patients undergoing radical cystectomy from 2011

Table 5 Variables, their options and proportions, and variable capture ratios in the standardised form for 5 years follow-up for non-muscle invasive bladder cancer (NMIBC) of the SNRUBC in the BladderBaSe 2.0

Variable	Options (proportions)	Recorded years*: capture ratio
Code for reporting hospital	Hospital codes	2004–2014: 70–89%
Reporting date	Date	2004–2014: 90–99%
Recurrence	No: 53.7% Yes: 46.3%	2004–2014: 81–92%
Date of recurrence*	Date	2004–2014: 100%
Progression	No: 91.7% Yes: 8.3%	2004–2014: 57–84%
Date of progression*	Date	2004–2014: 94–100%

*Year of diagnosis of the bladder cancer cases.
BladderBaSe, Bladder Cancer Data Base Sweden; SNRUBC, Swedish National Register for Urinary Bladder Cancer.

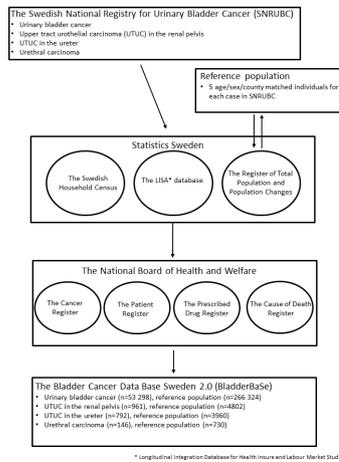


Figure 2 Flow chart of register linkages to construct the BladderBaSe 2.0. LISA, Labour Market Studies; SNRUBC, Swedish National Register for Urinary Bladder Cancer.

to 2019. Results of this validation are shown in online supplemental file 3.

Validation of postoperative complications of radical cystectomy in the SNRUBC as compared with medical charts

Data on postoperative complications, readmission rates, and death in with 90 days from radical cystectomy was validated by a comparison between data in the SNRUBC and medical charts in two healthcare regions in Sweden in 2011 to 2016.¹⁸ The study included 429 randomly selected patients from a larger cohort of 949 patients and showed under-reporting in the SNRUBC of low-grade complications (Clavien-Dindo I–II), and readmissions, but less under-reporting of high-grade complications (Clavien-Dindo III–V).

Limitations

BladderBaSe 2.0 lacks information on tobacco and alcohol exposure. We have proxy information in the linked registers for these exposures consisting of data

regarding diagnoses or medications for tobacco-related and alcohol-related diseases. However, these proxies will not adjust for all confounding by smoking and alcohol use. Additionally, we only have limited patient reported outcome measures. However, distribution of the validated Swedish version of the Functional Assessment of Cancer Therapy Scale Vanderbilt Cystectomy Index prior to radical cystectomy and 12 months postoperatively has been initiated on a national basis.¹⁹ Furthermore, as noted above, for some sites of the urinary tract we miss information for approx. 10% of the patients. However, we have to date no information to tell us that these are extreme outliers that would threaten the external validity for studies of patients with cancers at these sites. Another limitation is lack of molecular information for the cancer cases.

A limitation within the SNRUBC is that the tumour stage at progression for patients with NMIBC progressing to muscle-invasive disease is registered only from 2004 and onwards. However, the clinical tumour stage can also be ascertained from the radical cystectomy form for patients undergoing secondary cystectomy at progression. In addition, short follow-up time for recently introduced novel oncological systemic immunotherapies for advanced disease reduce the possibility to do studies with survival outcomes in these patients.

COLLABORATION

The steering group of the SNRUBC and the project group working with the BladderBaSe 2.0 are open for collaborations with national and international colleagues. For more information please access the SNRUBC website,² or contact the corresponding author. De-identified data can be available to researchers after application to the BladderBaSe Steering Committee. Researchers have to provide a methodologically sound proposal for a project that conforms with the Swedish Ethical Review Authority

Table 6 Retrieved register information linked to both cases and reference populations from nation-wide healthcare and demographic registries included in the BladderBaSe 2	
National registries	Retrieved data
The Cancer Register	Data on all cancer diagnoses including site and date.
The Patient Register	Inpatient and outpatient data on diagnoses, medical procedures and surgeries that may be related to risk, treatment effects and survival of cancer in the urinary areas, including diagnoses to calculate Charlson Comorbidity Index.
The Prescribed Drug Register	Data of drugs for hormonal treatment, antibiotics, osteoporosis treatment, psychiatric drugs, tuberculosis and cancer treatment, and data of all medications to calculate the Drug Comorbidity Index ¹ .
The Cause of Death Register	Date of death, and underlying and contributing causes of death
Swedish Household Census	Data from 1990 of socioeconomic status and profession
Longitudinal Integration Database for Health Insurance and Labour Market Studies	Annual data with socioeconomic factors such as marital status, education level and annual income
Register of Total Population and Population Changes	Randomly selection of reference group matched on sex, birth year, and region. Data on immigration and emigration.
BladderBaSe, Bladder Cancer Data Base Sweden.	

**Table 7** Baseline data of bladder cancer cases and their reference population in the BladderBaSe 2.0

	Cases (n total=53 298)		Reference group (n total=266 324)	
	N	%	N	%
Gender*				
Men	39 751	75	198 608	75
Women	13 547	25	67 716	25
Diagnosis/index year*				
1996–2004	15 730	30	78 602	30
2005–2012	17 930	34	89 595	34
2013–2019	19 638	37	98 127	37
Age at diagnosis/index date*				
64 and below	11 469	22	57 412	22
65–69	7 579	14	37 770	14
70–74	9 568	18	47 874	18
75–79	9 806	18	48 932	18
80–84	8 158	15	40 856	15
85 and above	6 718	13	33 480	13
Marital status				
Unmarried/single	5 626	11	30 771	12
Married/registered partners	30 485	57	154 221	58
Divorced/widowed	17 129	32	81 113	30
Missing	58	0	219	0
Education level				
Mandatory school	22 785	43	110 393	41
High school	19 517	37	94 886	36
University	9 585	18	53 780	20
Missing	1 411	3	7 265	3
Birth country				
Sweden	46 575	87	235 248	88
Other nordic country	2 345	4	11 946	4
Europe without nordic countries	3 121	6	12 501	5
World outside Europe	1 254	2	6 610	2
Missing	3	0	19	0
Charlson Comorbidity Index†				
No comorbidity (0)	28 166	53	167 935	63
Mild comorbidity (1)	8 895	17	37 713	14
Intermediate comorbidity (2)	9 078	17	34 910	13
Severe comorbidity (>2)	7 159	13	25 766	10
Drug Comorbidity Index‡				
Below 1.5	18 823	35	112 791	42
1.5 up to 3	8 708	16	33 203	12
3 and above	6 929	13	26 198	10
Missing	18 838	35	94 132	35

*Matching variables for reference group selection.

†Calculated based on diagnoses recorded in the patient register within 10 years prior to diagnosis/index date.

‡Calculated based data on prescribed drugs according to Gedeberg *et al*⁵ for patients with diagnosis/index date after 1 July 2006. BladderBaSe, Bladder Cancer Data Base Sweden.

Table 8 Publications based on the BladderBaSe version 1.0

Title	Journal, year	Conclusion
Improved long-term outcome of patients with non-muscle invasive, low and medium risk bladder cancer between 1997 and 2014; A Swedish Population-based Study.	Scand J Urology, 2022	Half of the patients had a recurrence. Rates were high in the first 2 years after diagnosis and very rare after 5 years of follow-up. Rates decreased in the last time period studied. Mortality was mostly due to non-bladder cancer related disease. Grade was the most important prognosticator for long-term outcome.
Risk of bladder cancer death in patients younger than 50 with non-muscle-invasive and muscle-invasive bladder cancer	Scand J Urology, 2021	Patients diagnosed with non-muscle-invasive bladder cancer when aged <50 are at decreased risk of bladder cancer-specific death when compared with their older (50-70) counterparts
Bladder cancer recurrence in papillary urothelial neoplasm of low malignant potential (PUNLMP) compared with G1 WHO 1999: a population-based study	Scand J Urology, 2021	The difference in risk of recurrence between primary stage TaG1 and PUNLMP stands in contrast to the recently adapted notion that treatment and follow-up strategies can be merged into one low-risk group of NMIBC.
Cumulative incidence of ureteroenteric strictures after radical cystectomy in a population-based Swedish cohort.	Scand J Urology, 2021	Ureteroenteric strictures requiring intervention may be more common than previously reported, affecting nearly one fifth of patients who have undergone RC for UBC. The annual incidence was highest in the first 2 years after surgery but the cumulative incidence increased continuously during 17 years of follow-up.
Survival after radical cystectomy during holiday periods	Scand J Urology, 2021	Same survival after radical cystectomy during holiday periods.
Cumulative incidence of midline incisional hernia and its surgical treatment after radical cystectomy and urinary diversion for bladder cancer: A nationwide population-based study	PloS One, 2021	The cumulative incidence of midline incisional hernia (MIH) was 8% 3 years postoperatively, and increase over time. Avoiding postoperative wound dehiscence after midline closure is important to decrease the risk of MIH.
A Population-based Study on the Effect of a Routine Second-look Resection on Survival in Primary Stage T1 Bladder Cancer.	Scand J Urology, 2021	We found similar survival outcomes in patients with and patients without second-look Resection (SLR), but our study is likely affected by selection mechanisms. A randomised study defining the role of SLR in stage T1 BCa would be highly relevant to guide current praxis.
Thromboembolism in Muscle-Invasive Bladder Cancer. A Population-based Nationwide Study	Bladder Cancer, 2021	Cumulative incidence thromboembolism increased 2 years after diagnosis, and was commonly observed after 30 days from diagnosis and from first treatment date.
Treatment and prognosis of bladder cancer patients with other primary cancers. A nationwide population-based study in the BladderBaSe	BJU International, 2020	Other concomitant or previous primary cancers is common in bladder cancer patients, but carries just as high chance of treatment success as in patients with only bladder cancer.
A mediation analysis to explain socio-economic differences in bladder cancer survival	Cancer Medicine, 2020	Mediation analysis suggests that the association between socio-economic status (SES) and BC survival can be explained by several factors.
Radical cystectomy compared with intravesical BCG immunotherapy for high-risk NMIBC—is there a long-term survival difference? A Swedish nationwide analysis	Scand J Urology, 2019	Improved cancer-specific survival after BCG compared with radical cystectomy in high-risk non-muscle invasive disease is probably related to selection mechanisms in the investigated population.
Sex Differences in Urothelial Bladder Cancer Survival	Clinical Genitourinary Cancer, 2020	Excess bladder cancer mortality in females with muscle-invasive bladder cancer.
Period-specific mean annual hospital volume of radical cystectomy is associated with outcome and perioperative quality of care: a nationwide population-based study	BJU International, 2019	With period-specific mean annual hospital volume (PSMAV) as a continuous variable, OS was improved for every increase of 10 RCs annually (HR 0.95, 95% CI 0.90 to 0.99). Moreover, higher PSMVA was associated with increased use of extended lymphadenectomy, continent reconstruction and use of neoadjuvant chemotherapy.
Management and outcome of muscle-invasive bladder cancer with clinical lymph node metastases. A nationwide population-based study in the BladderBaSe	Scand J Urology, 2019	Decreased use of treatment with curative intent in patients with lymph node metastases, but among those receiving such treatment the combination of chemotherapy and cystectomy has increased during later years.
Neoadjuvant chemotherapy for muscle invasive bladder cancer: a nationwide investigation on survival	Scand J Urology, 2019	Similar survival with or without neoadjuvant chemotherapy.
Management and outcome of TaG3 tumours of the urinary bladder in the nationwide, population-based bladder cancer database Sweden (BladderBaSe)	Scand J Urology, 2019	An underuse of adjuvant instillations in stage TaG3-disease was associated with decreased cancer-specific survival.
Survival after radiotherapy vs radical cystectomy for primary muscle-invasive bladder cancer: A Swedish nationwide population-based cohort study	Cancer Medicine, 2019	When taking into account unmeasured confounding by instrumental variable analysis, no differences in survival was found between the treatments for a selected group of patients.
A Nationwide, Population Based Analysis of Patients with Organ Confined, Muscle Invasive Bladder Cancer Not Receiving Curative Intent Therapy in Sweden from 1997 to 2014	Journal of Urology, 2019	Patients not treated with curative intent are frequently hospitalised during their final year of life and primarily die of bladder cancer.

BladderBaSe, Bladder Cancer Data Base Sweden; NMIBC, non-muscle invasive bladder cancer.

permit for the project. Researchers will have to sign a data access agreement. Data to achieve the aims in the approved proposal will be made available at a secure remote server.

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Acknowledgements This project was made possible with help of the data collected in the SNRUBC, and we would like to thank the steering committee, and all involved that support the SNRUBC. We thank Hans Garmo for calculations of the Drug Comorbidity Index 5. We also thank Pia Mårtensson-Löthgren, Anton Svensson, and Therese Lithner for organising the data deliveries from their different authorities.

Contributors CH, LH, FL and OH initiated the study and drafted the manuscript. TG, FA, VS, AH, AS, P-UM, KS, AU, TJ, SJ, FL and LH contributed with data and CH and OH analysed data. All authors revised the manuscript and approved the final version to be published. LH is the guarantor of the study.

Funding This work was supported by the Swedish Cancer Society, grant number CAN 2019/62 and CAN 2020/0709.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study was approved by The Research Ethics Board at Uppsala University, Sweden. (Dnr 2015-277, 2019-03574, 2020-05123, and 2022-01747-02)

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. Reports from the SNRUBC are available online (only in Swedish). Researchers can apply for data by submitting a proposal to the BladderBaSe 2.0 steering committee and data files for studies can be uploaded to remote servers for secure analysis. For more information contact the corresponding author.

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