

ARTICLE



## Which data are available in central registries on bladder cancer patients in the five Nordic countries

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### ABSTRACT

**Objective:** The aim of this study was to give a collective overview on all available data sources on bladder cancer patients in the Nordic countries including the amount of detail and coverage.

**Methods:** National representatives from five Nordic countries were asked to fill out a questionnaire on available information regarding bladder cancer patients from databases in their respective countries. Additional information was retrieved from descriptions of the relevant registries.

**Results:** *Non-muscle invasive bladder cancer:* from all countries, information on stage and grade at transurethral resection of the bladder (TURB) could be retrieved. Details on procedures (TURB, instillation therapy, photodynamic diagnosis, and perioperative instillation) were varying within different databases. *Muscle invasive bladder cancer:* in all Nordic countries, detailed information on cystectomy patients could be retrieved but with variable registration of complications. Completeness of available information on oncological treatment (radiation, chemotherapy, and immunotherapy) were varying. *Oncological outcome:* Information on overall survival was available in all countries whereas recurrence-free survival and cancer-specific survival were available for some but not all patients depending on treatment modality.

**Conclusions:** Despite limitations, we found that it was possible to retrieve detailed information on diagnostics, treatment, and outcome for most aspects of bladder cancer in the Nordic countries on a population based, non-selected patient cohort.

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## Introduction

The incidence of bladder cancer and other urothelial cancers in the Nordic countries (Denmark, Norway, Sweden, Finland, and Iceland) is approximately 8,000 per year (incidence 2012–2016) [1]. Bladder cancer accounts for 90–95% of urothelial cancers [2]. Finland had the lowest incidence of 22.1 cases per year per 100,000 inhabitants and Denmark had the highest incidence of 37.5 cases per year per 100,000 inhabitants (Table 1). The total prevalence in the Nordic countries at the end of 2016 was 69,882 patients [1].

An overview of all Nordic cancer patients is possible through NordCAN [1]. NordCAN is a cancer database with information on incidence, prevalence, and mortality regarding different cancers in the Nordic countries [3]. The NordCAN database provides cancer data for clinical and research use and has specific analyses available for public use [3]. However, detailed information on treatment and procedures is not available through NordCAN but can be obtained from several other databases.

Each Nordic country holds data regarding bladder cancer patients in population-based national cancer registries, which register all types of cancer. Currently, Denmark and Sweden are the only countries with a detailed specific national bladder cancer database. All residents in the Nordic countries are given a unique personal identification number at birth or immigration [3]. All health care activities and vital status are registered according to this unique person identification. Relevant data on diagnosis, treatment, and outcome can be obtained at the individual patient level from miscellaneous relevant central registries with a coverage almost equal to the entire population.

The aim of this article is to give a collective overview on all available data sources on bladder cancer patients in the Nordic countries including the amount of detail and coverage.

## Methods

National representatives from all five Nordic countries in the Nordic Urothelial Cancer Research Group were asked to fill out

**Table 1.** Incidence and prevalence in the Nordic countries [1].

	Incidence (2012–2016)	Incidence per year per 100,000 population	Prevalence (at the end of 2016)	Prevalence per 100,000 population
DK	2,140	37.5	19,268	672
NO	1,608	30.8	13,600	514
SWE	2,905	29.5	25,848	508
FI	1,215	22.1	10,397	381
ICE	80	24.1	769	451

**Table 2.** Primary national databases for gaining information on bladder cancer patients.

	Year of establishment	Database	Estimated coverage	Reference	Registration	Auditing
DK	1942	Danish Cancer Registry	95%	[10]	Clinicians	[4]
	2012	DaBlCa-data	≈100%	[16]	Automatic data registration from central registries	[32]
NO	1952	Cancer Registry of Norway	93%	[10,9]	Medical staff, database staff	[9,11]
SE	1958	Swedish Cancer Registry	94.8%	[10,33]	Medical staff (not reimbursed)	[33]
	1997	Swedish National Register of Urinary Bladder Cancer (SNRUBC)	97%	[18]	Medical staff	[18]
	2015	BladderBaSe	97%	[18]	Automatic from SNRUBC and national healthcare and demographic registries	
FI	1952	Finnish Cancer Registry	97.4%	[10,14]	Clinicians, pathologists	
	2005	Finnish National Cystectomy Database	95%	[21]	Urologists	
ICE	1954	Icelandic Cancer Registry	99.7%	[10,15]	Trained staff, medical staff	[15]
	2014	Landspítali Cystectomy	≈100%	[22]	Urological staff	
	2016	Landspítali TURB	≈90%	[22]	Urological staff	

**Table 3.** Microscopic verification for national cancer registries [10].

	Cancer database	Founded	Percentage of microscopically verified (MV) cases (NORDCAN data 2009–2013) (%)
DK	Danish Cancer Registry	1942	95
NO	Cancer Registry of Norway	1952	94
SE	Swedish Cancer Registry	1958	98
FI	Finnish Cancer Registry	1952	93
ICE	Icelandic Cancer Registry	1954	95

a questionnaire (Supplement Table 1) for each existing database in their respective countries. The questionnaire included information on whether the database was national/local, voluntary/mandatory, and the estimated coverage of the population. Furthermore, it was divided into sections regarding details of information on patient characteristics, pathology, treatment (transurethral resection of the bladder (TURB), instillation therapy, radiation therapy, cystectomy, chemotherapy including neoadjuvant, and immunotherapy), and follow up. Further information on degree of details were retrieved directly from description of the relevant registries.

### Data sources

#### National cancer registries and other central registries in the Nordic countries

Table 2 gives an overview of year of establishment, estimated coverage, registration and auditing. Moreover, Table 3 gives a percentage of microscopically verified cases in national cancer registries.

**Denmark.** The Danish Cancer Registry is publically financed and contains data on cancer incidence in Denmark since 1943 [4]. The Registry is population based and has since 2004 been linked to the Danish National Patient Registry (Danish, Landspatientregisteret, DNPR), the Danish Pathology Registry, and the National Cause of Death Registry [3]. In 2008, The Danish Cancer Registry went through an extensive modernization and manual coding was partly replaced by automatic coding [4].

The DNPR contains information on diagnoses, hospitalization and length of stay, diagnostic procedures, and treatment at the hospital. Data from DNPR are used for national health registries, research, and surveillance of diseases and treatment [5]. The Central Person Registry (CPR) contains data on vital status and overall survival (OS) [6]. The Danish National Prescription Registry contains individual information on prescribed medication sold in Danish community pharmacies since 1994 [7].

Patobank is a national data bank containing information on all pathological anatomical procedures done by the pathological departments registered in SNOMED codes.

These data are automatically transferred to the Danish Pathology Registry, which was founded in 1997 [8].

**Norway.** The Cancer Registry of Norway (CRN) contains certain information on bladder cancer tumor characteristics and treatment, especially when merged with the Norwegian Patient Register (NPR) and the National cause of death registry. The CRN is publically financed. Bakken et al. [9] did a comparison of registered patients in the Norwegian Patient Register and the Cancer Registry of Norway which showed that the CRN had registered 93% of bladder, ureter, and urethra cancer patients in 2008. The CRN gets histology reports for every specimen containing cancer from all Norwegian pathology departments and has a proven coverage of 94% for all cancers [10] and a coverage of 98.2% for bladder cancer and other urothelial cancers [11]. Benign histology in former cancer patients is not routinely collected. However, re-procedures with benign histology can be identified by codes and dates in the NPR.

**Sweden.** The Swedish Cancer Register (SCR) is publically financed and tracks malignant tumors and certain benign tumors, and registration of newly detected cancer is mandatory for all health care providers. When new data are registered, the personal identification number is checked against the population register of Sweden. The SCR is not connected to the Cause of Death Register, but data from the SCR can be compared to data from the Cause of Death Register to estimate underreporting [12].

**Finland.** The Finnish Cancer Registry (FCR) was founded in 1952, publically financed, and has an official bladder cancer registry as part of the FCR [13]. This registry contains information on pathology, basic information on treatment (instillation therapy, cystectomy, and radiation), and information on recurrences and death. When looking at all newly registered cancers in 2009–2013, 93% were morphologically verified. The proportion of morphologically verified bladder and urinary tract tumors were 97.4% in 2009–2013 [14]. When looking at completeness of registration in the FCR for the same period by comparing to the Care Register for Health and Welfare, the completeness of the FCR was 95.3% [14].

**Iceland.** The Icelandic Cancer Registry is publically financed and contains few details regarding treatment of bladder cancer. In the period 2005–2009, 99.7% of the registered cases of bladder, ureter, and urethra cancer were morphologically verified in the Icelandic Cancer Registry [15]. This indicates that a high level of patients diagnosed with urothelial cancer have undergone biopsies in Iceland, and the registry has a high coverage.

#### *Official national bladder cancer databases in the Nordic countries*

**Denmark.** The Danish Bladder Cancer database (DaBlaCa-data) was established in 2012 and is a prospective nationwide quality database largely based on secondary data from

DNPR and the Danish Pathology Registry with an estimated coverage of close to 100% [16]. The database monitors the quality of treatment of patients diagnosed with invasive bladder cancer. Patients are allocated according to region and treatment center in order to estimate potential differences in quality between centers. DaBlaCa-data contain data on all new diagnoses of invasive bladder cancer irrespectively of treatment modality since 2012 and also includes all patients with non-invasive tumors since 2018 [17]. DaBlaCa-data are publicly financed while The Danish Cancer Society finances auditing.

**Norway.** A national bladder cancer registry is expected in 2021.

**Sweden.** The Swedish National Register of Urinary Bladder Cancer (SNRUBC) covers 97% of all new bladder cancer cases of all stages from 1997 to 2014 when compared to the Swedish Cancer Register [18]. Public resources fund the SNRUBC, and patients are registered in the database by manual registration. The report form regarding bladder cancer consist of five forms divided into information on diagnosis, treatment, cystectomy, 5-year follow up, and oncological treatment [19]. SNRUBC has treatment data on 98% of participants in the database [18].

**Finland.** Finland does not have a separate national bladder cancer database.

**Iceland.** Iceland is planning to translate the Swedish registration forms from the SNRUBC within the next year and will implement the registration of the same variables as in the SNRUBC.

#### *Other databases as source of bladder cancer patient data in the Nordic countries*

**Denmark.** In addition to DaBlaCa-data, local cystectomy databases corresponding to the five cystectomy centers in Denmark exist.

**Norway.** Norway has local cystectomy databases in few dedicated centers.

**Sweden.** Bladder Cancer Data Base Sweden (BladderBaSe) was constructed in 2015 and includes all data from SNRUBC 1997 to 2014 [18]. In BladderBaSe, data from SNRUBC are linked with national healthcare and demographic registries, which makes BladderBaSe include information on socioeconomic factors, comorbidity, readmissions, treatment, side effects, and cause of death [18]. An update of BladderBaSe is in progress and expected in 2021. BladderBaSe is financed by research grants.

**Finland.** Finland has a national radical cystectomy database, which collects data on radically operated patients. This is a research initiated radical cystectomy database financed by FinnBladder research group and is not government run.

Patients are identified by ICD-10 codes and surgical procedure coding [20]. The registry is retrospective and contains information from 2005 [21]. Currently, it is being updated to cover 2019. The coverage of the National Cystectomy Database is 95% of cystectomies in Finland when compared to the coverage of the FCR [21].

**Iceland.** A local cystectomy database was constructed in 2014 (Landspítali Cystectomy) and a corresponding TURB database was constructed in 2016 (Landspítali TURB). These databases are voluntary and have no funding. As all major surgeries and the majority of TURB are performed at one hospital in Iceland, the Landspítali Cystectomy covers 100% of cystectomies and Landspítali TURB covers approximately 90% of TURB in Iceland [22].

## Results

Table 4 gives an overview of available databases and data details on bladder cancer patients.

### Non-muscle invasive bladder cancer (NMIBC)

All Nordic countries have information on histological stage and grade of NMIBC at TURB. In 2009, a 5-year follow up was introduced within the SNRUBC regarding local recurrence and progression of NMIBC in Sweden. The first study using these data, of patients diagnosed in 2004–2007, was published in 2015 [23].

Non-invasive papillary tumors are included in the Cancer Registry of Norway [24]. The Finnish National Cystectomy Database includes information on histological grade of Ta or T1 but no information on concomitant CIS, and only patients undergoing cystectomy are included.

### Procedures

#### TURB

All Nordic countries register data on TURB. SNRUBC, BladderBaSe from Sweden and Landspítali TURB registry in Iceland report tumor diameter/size and number of tumors at primary TURB. In the same registries, re-resection after TURB is noted. This information can be retrieved from data algorithms based on Danish DNPR data and Norwegian NPR data.

#### Instillation therapy

Information is varying and limited in most countries. Most databases have information on BCG treatment (yes/no) and Norway, Sweden, and Finland include information on chemotherapy instillation. Iceland has no information on instillation therapy. DaBlCa-data include information on instillation therapy with BCG divided into tumor stage. If the patient is treated with cystectomy or radiation afterwards this is also registered. The number of days from instillation therapy with BCG to cystectomy or start of radiation therapy is registered.

Table 4. Overview of available databases and registered information on bladder cancer patients.

Database	Cystectomy				Systemic chemotherapy (including neoadjuvant)				Follow up					
	CCI	Stage	Instillation Yes/no	Robot-assisted/ open	Type of urinary diversion	Complications (CDC)	Recurrence after cystectomy	Details		Radiation therapy	Systemic immuno-therapy	RFS	OS	CSS
								Yes/no	(date, cycles, type/drug)					
DK	÷	x	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	x	÷
Danish Cancer Registry	x	x	x	x	x	÷	x	x	x	x	x	x	x	x
Central registries														
(DNPR, Danish Pathology registry, CPR)														
NO	x	x	x	x	x	÷	x	x	x	x	x	x	x	x
DaBlaCa-Data	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷
Cancer Registry of Norway	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷
Norwegian Patient Registry	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷
SWE	÷	x	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷
Swedish Cancer Registry	÷	x	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷
SNRUBC	x	x	x	x	x	x	x	x	x	x	x	x	x	x
BladderBaSe	x	x	x	x	x	x	x	x	x	x	x	x	x	x
FI	÷	x	x	÷	÷	÷	x	÷	÷	÷	÷	÷	x	÷
Finnish Cancer Registry	÷	x	x	÷	÷	÷	x	÷	÷	÷	÷	÷	x	÷
Finnish National Cystectomy Database	x	x	x	x	x	x	x	x	x	÷	x	x	x	x
ICE	÷	x	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷
Icelandic Cancer Registry	÷	x	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷
Landspítali Cystectomy	÷	x	÷	x	x	x	÷	÷	÷	÷	÷	÷	÷	÷
Landspítali TURB	x	x	÷	÷	÷	÷	÷	÷	÷	÷	÷	x	÷	÷

CCI: Charlson Comorbidity Index; CDC: Clavien Dindo Classification; CPR: The Danish Central Person Registry; CSS: cancer-specific survival; DNPR: The Danish National Hospital Register; OS: overall survival; RFS: recurrence-free survival; SNRUBC: Swedish National register of Urinary Cancer.

More details on number of cycles and maintenance can be retrieved through algorithms from DNPR data in Denmark.

### *Photodynamic diagnosis (PDD)*

The Danish and the Norwegian National Patient Registry, and the Icelandic Landspítali TURB database register use of PDD.

### *Perioperative instillation*

Perioperative instillation is registered in the Swedish databases SNRUBC and BladderBaSe, in the Danish and the Norwegian National Patient Registry, and in the Icelandic Landspítali TURB database. It is also registered in the Finnish National Cystectomy Database.

### *Follow up*

The 5-year follow-up registration of NMIBC in SNRUBC has a coverage of 88%. Date of first recurrence and progression is reported; number of recurrences is not reported [18]. DaBlCa-data have included follow up on non-invasive tumors and CIS since September 2018 [17].

In the case of recurrence, DaBlCa-data register the type and histopathology of first recurrence or progression after initial NMIBC. This database registers no information on number of subsequent recurrences. This information can be estimated from DNPR data. Data on histological confirmed recurrences are available in the Norwegian Cancer Registry.

### *Muscle invasive bladder cancer (MIBC)*

All five Nordic countries have information on MIBC patients, either through a national cancer database or through a national bladder cancer or cystectomy database. All countries register information on clinical stage at TURB in a national database (Iceland registers this information in the local TURB database in Reykjavik). In Norway and Sweden, this information is only available for primary tumors; in case of progression or recurrence, only the date is registered. The pathological stage after cystectomy is also registered in all countries. Iceland registers this in the local cystectomy database.

### *Procedures*

**Cystectomy.** SNRUBC has data regarding surgery details (pre-operative, perioperative and postoperative) and complications on 85% of patients treated with radical cystectomy as well as characteristics of the primary tumor at diagnosis and primary treatment [18]. DaBlCa-data contain some selected data on cystectomy patients but no direct information on complications other than 90 days mortality. Instead, surrogate markers like length of stay and incidence of re-admission is registered.

Swedish and Finnish national registries contain information on organ injury during cystectomy and 90 days postoperative complications. Iceland reports 90 days postoperative complications in the local cystectomy database, which is also the practice in local databases in Norway and Denmark.

Length of postoperative stay at the hospital is registered centrally in Sweden, Finland, Norway, and Denmark. Iceland register this information in the local database.

All Nordic countries register re-admission and re-operation. Iceland registers this in the local cystectomy database, and Norway obtains this information through the Norwegian Patient Registry. All Nordic countries register date of recurrence after cystectomy (Norway and Iceland report this in local databases and Sweden in BladderBaSe).

### *Oncological treatment*

**Radiation.** The Danish and Swedish bladder cancer databases are the only bladder cancer databases to include information on radiation therapy. In SNRUBC, it has been mandatory reporting since 2014. DaBlCa-data include detailed information on radiation therapy; whether this treatment is of curative intent, number of treatments and dates of start of treatment, and completion of treatment together with long-term survival, and oncological outcome. Norway has a national database on radiation but experience with output from the database on bladder cancer is lacking.

**Systemic chemotherapy.** All Nordic countries have some information on systemic chemotherapy in at least one of the mentioned databases. DaBlCa-data include information on neoadjuvant and palliative chemotherapy and registers the time from diagnosis to start of chemotherapy. The Cancer Registry of Norway includes information on primary palliative chemotherapy and includes information on neoadjuvant chemotherapy (NAC) by linking to the patient registry. The oncology registration form of SNRUBC contains detailed information on neoadjuvant, adjuvant, and palliative chemotherapy but the estimated coverage was 51% in 2019 [25]. This is considered significantly lower than for the other four registration forms in the SNRUBC. The Finnish National Cystectomy Database contains detailed information on neoadjuvant and adjuvant chemotherapy but no information on palliative treatment. The Icelandic Cancer Registry has no information on chemotherapy, though the local cystectomy database has information on NAC.

**Systemic immunotherapy.** Immunotherapy treatment and the startup date of treatment are registered in DaBlCa-data and in the oncology form of SNRUBC. The Norwegian Patient Registry registers the date, distribution, and ATC-code, but availability is currently limited. The Cancer Registry of Norway registers only primary palliative treatment.

### *Follow up*

All Nordic countries have a national database containing continuous follow up until death with varying details including date and cause of death. Data on OS are available from all national cancer registries. Sweden and Finland registers the date of out-patient visit; these are also available through the Norwegian Patient Registry. Information on recurrence-free survival (RFS) and cancer-specific survival (CSS) is available from Danish central registries and DaBlCa-data. Data



on recurrence after TURB are available from Swedish (SNRUBC, BladderBaSe), Danish (DNPR), Icelandic (Landspítali TURB), and Norwegian (Norwegian Cancer Registry) databases.

## Discussion

Data on treatment and prognosis are the foundation of national guidelines for treatment of bladder cancer. Possible future improvements in treatment regimens are therefore, in part based on analyses of available registry data. An absolute minimum of critical data must be registered in order to change possible future practice. Thus, databases should contain information on pathological stage, treatment, and follow-up regime. The registration of data must be based on identical criteria in order to compare data between databases and countries. This requires a specific and detailed guidance in database registration, e.g. if the pathological stage is registered from TURB, it should be noted whether this is from first resection or including potential upstaging at a later procedure.

Research databases often contain data on selected groups of patients and are, therefore, not necessarily useful for generalization. However, one of the strengths of the Nordic databases is the possibility of extracting information from national cancer databases with a coverage close to 100%. The SEER registries (USA) cover approximately 35% of the population of the United States [26]. The SEER contains data on bladder cancer from selective sites, unlike the Nordic cancer registries, it is not a national cancer registry with complete coverage. Al-Husseini et al. [27] did a SEER-based analysis on incidence and mortality of bladder cancer in the USA using the SEER 9 registries which cover 9.4% of the US population from 1975 to 2014 [28]. Since the SEER database, in this case, covers only approximately 10% of the US population, the results may differ according to the obtainable data.

Cheluvappa et al. [29] did an epidemiological evaluation of bladder cancer in Australia. As opposed to the SEER registries (USA) and most of the Nordic databases, the Australian databases do not register CIS. Bladder cancer survival rates may therefore be higher in countries that register CIS.

The Netherlands did a nationwide observational cohort study on bladder cancer patients [30]. The Dutch Cancer Registry identifies newly diagnosed bladder cancer patients by connecting data to the pathological registries in the Netherlands. However, the Dutch Cancer Registry does not register detailed data on diagnostic procedures and treatment, recurrence, and progression. The date of death is obtained by connecting to the Dutch Municipality Registration once every year [30].

Despite the high coverage of the Nordic databases, they also have several limitations. Andreassen et al. [31] estimated incidence and survival of urothelial carcinoma of the urinary bladder in Norway from 1981 to 2014 and found that The Cancer Registry of Norway was not able to distinguish between muscle-invasive (T2–T4) and non-muscle invasive (T1) bladder cancer. This problem will be solved in the future

edition of the Norwegian bladder cancer registry. In the SNRUBC in Sweden, patients are registered with 5-year follow-up after a diagnosis of NMIBC [18]. However, follow-up is not reported until after 5 years, and data on follow-up less than 5 years after diagnosis of NMIBC are, therefore, not available for the most recent patients. The DaBlaCa reports recurrence after treatment when patients are deceased. Consequently, this information is not available at the time of recurrence but at death of the patient only.

Even though the Nordic countries have similar databases with information on bladder cancer, these databases vary slightly in design and available information. Vast amounts of data must be discarded for analysis if not comparable between countries.

The NorCys is a prospective Nordic cystectomy validation study being implemented by *The Nordic Urothelial Cancer Group*. Registration of patients in this study may complement national and local cystectomy databases in all Nordic countries. This study will include detailed information on recurrence and complications at follow-up at 3 months, 2 years, and 5 years after cystectomy; this includes date of recurrence, whether recurrence is local/distant, and treatment of recurrence.

Different initiatives from the pharmaceutical industry aimed at merging and improving available data from registries are implemented to gain worldwide experience before launching of new pharmaceutical products. However, missing data are an important issue when comparing data on treatment between countries, and data completeness affects the quality of the data. Data can be incomplete either by missing records or by absent values in a record. Another issue is the introduction of new treatments. For example, immunotherapy is a relatively new treatment registered by procedure codes. The respective database will need to be updated with a specific procedure code in order to register new treatment in the national database. Usually, updates are run continuously.

## Conclusion

Despite limitations and both practical and legal restrictions when merging data, it is possible to retrieve detailed information on diagnostics, treatment, and outcome for most aspects of bladder cancer in the Nordic countries on a population-based, non-selected patient cohort. This can form the basis for true real-time cohort studies.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

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