Supplementary material to:

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Web Table 1. Nordic cancer registries, administrative facts and quality issues.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Official name	The Danish Cancer Registry	Cancer Society of Finland, Finnish Cancer Registry – Institute for Statistical and Epidemiological Cancer Research	The Icelandic Cancer Registry, the Icelandic Cancer Society	Cancer Registry of Norway, Institute of Population-based Cancer Research	Swedish Cancer Registry, the Swedish National Board of Health and Welfare
Founded	1942	1952	1954	1952	1958
Earliest year of registered cancer diagnosis	1943	1930 (previous malignancies for persons with cancer diagnosed 1953+; diagnoses of patients died from cancer 1953+)	1955 (breast cancer incidence also for 1911-1954, based on study by Snaedal 1965)	1952	1958
First year of incidence registration considered complete	1943	1953	1955	1953	1958
Link to web page	http://sundhedsdatastyrelsen.dk/da/registre-og-services/om-de-nationale-sundhedsregistre/sygedomme-laegemidler-og-	www.cancerregistry.fi	www.krabbameinsskra.is	www.kreftregisteret.no	http://www.socialstyrelsen.se/register/halsodataregister/cancerregistret

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	behandlinger/cancerregisteret				
How to contact the Cancer Registry?	cancerregisteret@sundhedsdata.dk	kirjaamo@cancer.fi	skra@krabb.is	kreftregisteret@kreftregisteret.no	cancerregisteret@socialstyrelsen.se
How to apply information from the cancer registry (with link to forms and instructions)?	Contact the Researcher service at the Danish Health Data Authority, email: forskerservice@sundhedsdata.dk.	Send a form (https://www.cancer.fi/@Bin/119098415/Tietopyynt%C3%B6+sy%C3%B6p%C3%A4rekisterille2015eng061015.pdf) to kirjaamo@cancer.fi	Send a form (http://www.krabbameinsskra.is/index.jsp?id=eydublod) Contact person: gudridur@krabb.is	Send a form (https://www.kreftregisteret.no/Registrene/Datautlevering/Soknadsskjema/). Contact datautlevering@kreftregisteret.no for information	Send a Form (http://www.socialstyrelsen.se/register/bestalladataochstatistik)
Links to documents on data protection principles. Survey 2000 (http://www.ancr.nu/cancer-data/cancer-registry-survey/): basic rules for confidentiality in Appendix 2	Information about data protection and privacy at the Danish Health: http://sundhedsdatastyrelsen.dk/da/borger-og-offentlighed/sikkerhed-om-dine-data			Information about data protection and privacy: https://www.kreftregisteret.no/Generelt/Om-Kreftregisteret/Personvern/	Information about data protection legislation. (http://www.socialstyrelsen.se/register/bestalladataochstatistik/bestallaindividuppgifterforforskningsandamal/omsekretessen)
Publications on data quality	Storm et al. 1997, Gjerstorff 2011	Teppo et al. 1994; Leinonen et al. 2017 (partly describing an exceptional period)	Sigurdardottir et al. 2012	Larsen et al., 2009	Barlow et al. 2009
Percentage of death certificate only (DCO) cases (NORDCAN data 2009-2013)	0.3%	1.2% in 2009-2011 (tracing of DCI data for 2012+ delayed)	0.3%	1.1%	0
Percentage of microscopically verified (MV) cases (NORDCAN data 2009-2013)	95%	93%	95%	94%	98%

Web Table 2. Data sources of the Nordic cancer registries (routine data collection).

	Denmark	Finland	Iceland	Norway	Sweden
Public hospitals	Yes (received automatically from Danish Patient Register 2004+)	Yes (automatic reporting from some hospital registers since late 1980s, still mostly manual)	Registrars have direct access to electronic medical records for completing registration and information on stage	Yes (manual reporting, mostly electronically)	Yes
Private clinicians	Yes	Yes	Yes, only for prostate cancer, manual reported on paper	Yes (manual reporting, mostly on paper)	Yes
Dentists	Yes	Yes	No	No	No
Inpatient registry	Yes	No[1]	2000+ (automatic reporting)	1998+ (in- and outpatients)	No
Laboratories, pathological reports	Yes (for cases coded 2004+)	Yes (automatic reporting from almost all laboratories since late 1980s)	Yes (automatic reporting)	Yes (automatic reporting, both paper and electronically)	Yes
Laboratories, haematological reports	No	Yes	Yes (automatic reporting)	No (only samples sent to pathological laboratories)	Yes
Laboratories, cytological reports	No	Yes	Yes (automatic reporting)	Yes (automatic reporting, both paper and electronically)	Yes
Death certificates	Yes	Yes (automatic reporting from Statistics Finland 1981+)	Yes (automatic reporting from Statistics Iceland until 2009 and from Directorate of Health 2010+)	Yes (automatic reporting, data file and picture files of death certificates)	No
Radiotherapy data (from all machines)	No	No	No	1997+[2]	No

[1] Trial use 1985-1988: after validation process 965 cancers added. Since 2015 the hospital discharge data 1996+ have been available for cross linkage with the Cancer Registry and can be used to complement possibly missing cases and to confirm DCI-cases.

[2] Data items: region where treated; diagnosis (ICD-10); intention of treatment; date for start of treatment; number of days for treatment; date for end of treatment; total dose; total number of fractions.

Web Table 3. Numbers of cancers and other disease entities collected by the Nordic cancer registries, 2009-2013. The percentages *in Italics* indicate the difference between the national routine statistics publications and NORDCAN.

Disease / disease group	Number of registered cases in 2009-2013				
	Denmark	Finland	Iceland	Norway	Sweden
1. NORDCAN cancer entities* (NORDCAN 7.3; Engholm et al. 2016)	**186,141**	**150,441**	**7,360**	**146,007**	**272,658**
Additional cancers / disease entities registered but not included in NORDCAN tabulations					
2. Cancers registered in the national registries, but not included in NORDCAN					
2.1 Multiple cancers in same organ group**	1,823	2,089	[147]	[4,309]	24,714
2.1.1 Breast (*addition to the NORDCAN count*)	555 *(2.2%)*	1,261 *(5.6%)*	[81] *(7.7%)*	[1,240] *(8.3%)*	6,983 *(19.9%)*
2.1.2 Skin, melanoma	0 (if there is a second skin melanoma, the topography code of the first skin melanoma is changed to C43.8 "multiple locations")	106 *(1.7%)*	0 (only the first case is registered)	[687] *(8.3%)*	1,181 *(8.0%)*
2.1.3 Skin, non-melanoma, excluding basal cell carcinoma	0 (if there is a second non-melanoma skin cancer, the topography code of the first non-melanoma is changed to C44.8 "multiple locations")	576 *(7.8%)*	0 (only the first case is registered)	[165] *(2.2%)*	7,846 *(38.9%)*
2.1.4 Colon	390 *(2.8%)*	31 *(0.3%)*	[21] *(4.2%)*	[814] *(6.2%)*	1,728 *(8.8%)*
2.1.5 Bladder etc. (ICD-10: C65-68+D09.0-1+ D30.1-9+D41.1-9)	749 *(7.6%)*	91 *(1.6%)* (includes *in situ* and PUNLMP cases)	[26] *(6.9%)*	[423] *(6.2%)*	820 *(6.1%)*
2.2 Polycythaemia vera (to be included in NORDCAN cancer entities in Fall 2017)	678	376	[14]	[349]	793
2.3 Skin, basal cell carcinoma	58,208	40,866	[1,671]	[40,606] (not stored in the actual Cancer Registry data base)	208,985

Disease / disease group	Number of registered cases in 2009-2013				
	Denmark	Finland	Iceland	Norway	Sweden
2.4 Other excluded categories	Myelodysplastic syndrome: 1,264; Other not specified tumours in lymphatic and and haematopoietic tissue: 1,344 (In NORDCAN edition in Fall 2017 there will be new categories for these cancer entities.	43	0	89	
3. Premalignant or borderline diseases registered in the national registries but not included in NORDCAN					
3.1 Ovary, borderline cancer	[880]	767	[39]	[788] + [318 other premalignant ovarian tumours]	810
3.2 Cervix uteri, precancerous lesions / *in situ*	26,835/2,648	5,872	[25]	[60,674]	14,568 (CIN III)
3.3 *In situ* cancers, excluding cervix uteri	2,516 (only breast)	2,732 (only breast) [423, excluding breast and bladder; registered for all organs except skin]	[618] [breast:100, melanoma: 96, other skin: 422]	[23,699]	[20,872]
3.4 Mola and neoplasma placenta	363			16	
4. Other registrations					
4.1 Cancers of persons living abroad	0	[567]	[23]	[305]	0
4.2 Preregistered possible cancers, waiting for additional data to confirm the diagnosis	0	[69]	0	0	0

* Taken from NORDCAN 7.3 (Engholm et al. 2016). National exceptions from strictly comparable joint Nordic registration principle: see http://www-dep.iarc.fr/NORDCAN/english/frame.asp?o=database.

** See IARC/IACR multiple coding rules, organ grouping in multiple coding (http://www.iacr.com.fr/images/doc/MPrules_july2004.pdf)

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Web Table 4. Variables on cancer **patients** registered by the Nordic cancer registries.

Yellow background: This information is not directly available (in a qualitatively accurate manner) but may be derived from other sources with a modest extra effort.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Personal identity code (PIC)	Available for persons alive and living in DK from 1968 (checked with PR)	Available for persons not died before 1967 (checked with PR); before that homemade PICs.	Available for persons not died before 1 Dec 1965+ (before that homemade PICs)	Available for persons alive from 1964. The Cancer Registry gets monthly updates from the population register. Only cancer cases for persons registered in the population register are included. Notifications for persons without a valid birth number/ PIC are saved in a queue, and checked against PR for a few years before they are deleted if no match can be found.	Yes (checked with PR)
Date of birth	Yes	Yes	Yes	Yes	Yes
Sex	Yes	Yes	Yes	Yes	Yes
Place of residence (unit)	Yes (1968+: municipality registered in PR at date of cancer diagnosis; 1968-2006: county; 2007+: region)	Yes (municipality in the beginning of year of cancer diagnosis searched from PR). Plan to use coordinate-based place of residence information, with residential history.	Yes (1955+: municipality; 2016+: postal code)	Yes (municipality of residence January 1st the year of diagnosis, incomplete before 1971). Since 1990 also "grunnkrets" (smaller unit than municipality).	Yes (county, municipality, parish)

Variable	Denmark	Finland	Iceland	Norway	Sweden
Occupation	Available until 2003. Can be retrieved from SO.	Yes (from SO for patients who participated population census 1975 or later)	No	No. Information was collected in cancer notification but with incomplete reporting, so registration ended in 2011/2012. Information on occupation can be linked from Statistics Norway for specific research projects after research approval.	No
Education	No. Can be retrieved from SO.	Yes (from SO for patients who participated population census 1975 or later)	No	No. Information on education can be linked from SN for specific research projects after research approval.	No (Received via record linkage with SO when needed)
Socio-economic position	No. Can be retrieved from SO.	Yes (from SO for patients who participated population census 1975 or later)	No	No. Information on income can be linked from SN for specific research projects after research approval.	No (Received via record linkage with SO when needed)
Date of immigration	No (available from PR if needed)	Yes (from PR for patients not died before 1967)	No	Yes, from 2015	Yes
Country of origin	No (available from PR if needed)	No (available from PR if urgently needed)	No	No (could be obtained from linkage with SO or PR, but there are strict restrictions for access)	No
Country of birth	No (available from PR if needed)	Yes (from PR for patients not died before 1967)	**Yes**	No (could be obtained from linkage with SO or the population register, but there are strict restrictions for access to this parameter)	Yes
Date of emigration	Yes	Yes (from PR for patients not died before 1967)	No	Yes	Yes
Vital status	Yes (for each registered person it is checked that he exists in the PR alive, emigrated of died)	Yes (for each registered person it is checked that he exists in the PR alive, emigrated of died)	Yes (for each registered person it is checked that he exists in the PR alive or dead)	Yes. Monthly updates from PR allow updated status for persons who are alive and living in Norway, emigrated or dead.	Yes (date of death/migration from SO)
Date of death	Yes	Yes (from SO)	Yes	Yes (both from PR and from the Cause of Death Registry at National Health Institute)	Yes

Variable	Denmark	Finland	Iceland	Norway	Sweden
Underlying cause of death	No (available from Death Cause Registry at National Health Data Authority).	Yes (from SO)	Yes (but only for those who die from cancer)	Yes (from the Cause of Death Registry)	Yes (from the Swedish Cause of Death Register at the National Board of Health and Welfare)
Other causes of death	No (available from DCR and Pathology Registry at National Health Data Authority)	Yes (from SO)	Yes (from 2003) but only if the cause is cancer	Yes (from the Cause of Death Registry)	No (available from the cause of death registry at the National Board of Health and Welfare)
Autopsy	Included in macro verification variable	Yes	Yes	Yes for medical autopsies, not for forensic autopsies	Yes

External linked sources:
PR: Population Register
SO: Statistical Office (Statistics Denmark/Finland/Iceland/Norway/Sweden)

Web Table 5. Variables related to each **cancer** registered by the Nordic cancer registries.

Yellow background: This information is not directly available (in a qualitatively accurate manner) but may be derived with a modest extra effort.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Date of diagnosis	1943-2003 only month and year.	Before 2014 only month and year[F1]	Day-month-year	Day-month-year	Day-month-year
Topography / primary site	1943-1977: ICD-7, modified. 1978 - 2003; ICD-O-3, based on conversion of ICD-O-1 and ICD-O-2. From 2004; ICD-O-3	ICD-O-3 (for most cancers diagnosed before 2007 the ICD-O-3 code was translated from ICD-7 via a conversion matrix; translated codes do not always offer as detailed cancer categories as the ICD-O-3 nomenclature would allow)	1955-1979: ICD-7; 1980 - 1982: ICD-9; 1983- 1989: ICD-O-1; 1990-2002: ICD-O-2; 2003+: ICD-O-3. All codes have been converted to ICD-10 for purposes of reporting and communication.	ICD-0-3 (In addition localization of ICD7: More detailed site of the neoplasm, e.g.. extralymphatic localization, extragonadal germ cell tumours	1958+: ICD7, 1987+: ICD9, 1993+: ICD-O-2, 2005+: ICD-O-3
Morphology / histology	1943-1977: ICD-7, modified. 1978 - 2003; ICD-O-3, based on conversion of ICD-O-1 and ICD-O-2. 2004+; ICD-O-3	ICD-O-3 (plus some newer ICD-O codes not in ICD-O-3 and previously some self-made additional codes for registered disease entities that are not in ICD-O-3). For most cancers diagnosed before 2007 the ICD-O-3 code was translated from MOTNAC via a conversion matrix; translated codes do not always offer as detailed cancer categories as the ICD-O-3 nomenclature would allow.	1955-1979: ICD-7; 1980 - 1982: ICD-9; 1983- 1989: ICD-O-1; 1990-2002: ICD-O-2; 2003+: ICD-O-3. All codes have been converted to ICD-10 for purposes of reporting and communication.	ICD-0-3 (plus some additional self-made codes)	1958+: C24.1*, 1993+: ICD-O-2, 2005+:ICD-O-3 *WHO Histological classification of neoplasms (WHO/HS/CANC/24.1), Geneva 1956
Behaviour / malignancy	1943-1977, ICD-7. 1978+: ICD-O-3	ICD-O-3: 0 Benign; 1 Semimalignant (Borderline malignancy, Low malignant potential, Uncertain malignant potential); 2 Carcinoma in situ (Intraepithelial; Noninfiltrating; Noninvasive); 3 Malignant	ICD-O-3: 0 Benign; 1 Semimalignant (Borderline malignancy, Low malignant potential, Uncertain malignant potential); 2 Carcinoma in situ (Intraepithelial; Noninfiltrating; Noninvasive); 3 Malignant	ICD-O-3 0 Benign 1 Uncertain whether benign or malignant Borderline malignancy Low malignant potential 2 Carcinoma in situ Intraepithelial Non-infiltrating Non-invasive 3 Malignant, primary site	0' Benign; '1' Semimalignant (Borderline malignancy, Low malignant potential, Uncertain malignant potential); '2' Carcinoma in situ (Intraepithelial; Noninfiltrating; Noninvasive); '3' Malignant

Variable	Denmark	Finland	Iceland	Norway	Sweden
Method of confirmation	Self-made code[D1]	Self-made code[F2]	ENCR recommendations, Vol.1 (2003) https://www.iarc.fr/en/publications/pdfs-online/treport-pub/treport-pub40/IARC_Technical_Report_No40_0.pdf	Self-made code[N1]	'5' Autopsy, microscopical; '3'Histology from primary tumour; '5' Cytology; '8' Laboratory finding; '7' Autopsy, macroscopical; '6' Surgery; '2' X-Ray; '1' Clinical;
Stage at diagnosis	Before 2004, self-made codes (localised, regional, metastasis, unknown, Dukes). 2004+ TNM and Ann Arbor	Self-made code: 0 Unknown; 1 Localized; 2 Metastases in regional lymph nodes only; 3 Metastases further than in regional lymph nodes or tumour invades adjacent tissues; 4 Non-localized, unspecified. In 2012 two additions to the code: 5 Locally advanced, tumour invades adjacent tissues; 6 Distant metastasis	No (see TNM↓)	Self-made code[N2]; detailed UICC staging for breast cancer (1953/1986 -->), cervical cancer (1953/1991 -->), ovarian cancer (2002 -->) and lymphomas (1953/1993 -->)	No (see TNM↓)
TNM	Since 2004	No[F1] (Since 2017 TNM is coded as a combination of clinical and laboratory notifications. Information is incomplete.)	TNM stage according UICC (AJCC) , 7th edition, for following sites since 2010: Colon-Rectum, Breast, Melanoma, Prostate and Cervix (Figo). Previous years available for those sites along Thyroid.	Yes. Clinical TNM has been registered when reported, but information is incomplete. Pathologic TNM is only registered for the following cancer sites: Rectal cancer: from 1993 Breast cancer: from 1986 Prostate cancer: from 2003 Colorectal cancer: from 2007 Lung cancer: from 2013	Since 2004
Later Metastases, recurrences	No (can be studied with linkage to the National Patient Discharge Registry, validity not perfect)	No[F1] (can be studied with linkage to the national Care Register, validity not perfect)	No (can be obtained with considerable work, co-operating with clinicians).	No (can be studied with linkage to the national Patient Register). Metastases with confirmed histology are available. Several quality registries now ask for clinical information about recurrence, but the completeness is still not good.	No

Variable	Denmark	Finland	Iceland	Norway	Sweden
Treatment	Available before 2004 (2004+ can be studied through linkage to the National Discharge Registry)	Treatment started during the first year after diagnosis: self-made coding system[F3]. From 2016-2017 onwards NCSP-codes. The completeness of this information is so low and has decreased over the years, i.e., it can only be utilised for specific purposes with caution.	Only for prostate cancer since the year 1999; first treatment within 6 months from diagnosis.	Treatment started during the first year after diagnosis; self-made codes[N3]	No (can be studied with linkage to the national Patient Register)
Symptoms	No	No (Date of first symptoms was asked in cancer notification from the hospitals but it was so incomplete that it is has not been used lately. It is possible to identify cancers diagnosed in organised screening via record linkage with Mass Screening Registry.)	No	Information was collected in cancer notifications but with incomplete reporting; registration ended in 2011/2012. For melanomas, symptoms are still registered. There are also some questions about "reason for diagnostics" in some of the other quality registries. This variable might contain some information about symptoms.	No
Other	More detailed information may be available from the registries of 22 clinical cancer groups (www.DMCG.dk)	Code for evaluating cancer mortality (died of this cancer; died of other causes).		More detailed information available from quality registries: Childhood cancers 1985+, Rectal cancer 1993-2006, Ovarian cancers 2002+, Prostate cancer 2004+ Colorectal cancer 2007+ Melanoma 2008+, Breast cancer 2009+, Lymphoma and lymphoid leukaemia 2011+, Lung cancer 2013+ Oesophagus and stomach 2015+	More detailed information available from >25 clinical INCA registries (Web Table 7)

Specifications to web table 5:

D1 Denmark, Method of confirmation

Macroscopic confirmation

Before 2003
A Unknown at time of registration
0 Clinical investigation only
1 X-ray examination
2 Endoscopy
3 Surgery
4 Autopsy, already known neoplasm
5 Autopsy, incidental finding
6 Autopsy, unknown whether incidental or already known
7 Other specified (ultrasound, scintigraphy, MR, etc.)
8 Death certificate only
9 Histologic examination alone

From 2004
AZCK0 Surgery
AZCK1 Endoscopy/Surgery
AZCK2 Diagnostic imaging
AZCK3 Autopsy
AZCK4 Clinical investigation only
AZCKX Not relevant for present report

Microscopic confirmation

Before 2004
A Unknown time of registration
0 No Histologic confirmation
1 Histology from primary neoplasm
2 Histology from metastasis
3 Histology, unknown if primary neoplasm or metastasis
4 Cytology from primary neoplasm
5 Cytology from metastasis
6 Cytology, unknown if primary neoplasm or metastasis
7 Peripheral blood speciment
8 Bone marrow

From 2004
AZCL0 Histology/cytology from primary neoplasm
AZCL1 Histology/cytology from metastasis

AZCL2 Histology/cytology, unknown if primary neoplasm or metastasis
AZCL3 Other clinical/histological examinations
AZCL9 No histology/cytology/clinical-histology
AZCLX Not relevant for present report

F1 Finland

More detailed information can be derived from the database which includes all information received on the cancer notifications (mainly free text).

F2 Finland, method of confirmation from 2017 onwards

7	Histological examination from primary tumour
8	Histological examination from autopsy specimens
6	Histological examination of metastasis
5	Cytological
4	Specific tumour markers
2	Clinical, including imaging diagnostics
1	Clinical
0	Death certificate only
9	Unknown
10	Flow cytometry
12	Moleculargenetic analysis
13	Immunophenotyping

For cancers coded before 2017, selected in order of following reliability:
4 Histology from primary tumour
5 Autopsy, microscopical
7 Histology from metastasis
6 Cytology
9 Laboratory finding
8 Autopsy, macroscopical
2 Surgery
3 X-Ray
1 Clinical
0 Unknown
Before 2014 histology from autopsy was considered as most reliable method.

F3 Finland, coding of treatment

(incomplete data; can be better studied with linkage to the National Care Register)

Surgical treatment

0 no treatment
1, 4, 7 Radical

2, 5, 8 Palliative
3, 6, A Not known whether radical or palliative
9 Not known whether treated
NB: Codes 1, 2, 3 indicate treatment within 4 months of diagnosis. Codes 4, 5, 6 indicate treatment starting more than 4 months after diagnosis. Codes 7, 8, A indicate that we do not know when the treatment started.

Radiotherapy

Codes as for surgical treatment

Cytostatic drug treatment

0 no treatment
1 treatment within 4 months of diagnosis
4 treatment starting more than 4 months after diagnosis
7 not known when treatment started
9 not known whether treated

Hormone treatment

Codes as for cytostatic drug treatment

Other treatment

Codes as for cytostatic drug treatment

N1 Norway, Method of confirmation

00 Clinical examination without additional examinations outside a hospital
10 Clinical examination without additional examinations in a hospital
20 Imaging diagnostics (x-ray, Ultrasound, CT, MR)
22 Clinical notification about cytological examination
29 PSA test
30 Biochemical examination, electrophoresis
31 Endoscopic examination
32 Cytological examination of primary tumour
33 Blood smear
34 Bone marrow smear
35 Examination of spinal fluid
36 Cytological examination of metastasis
37 Cytological examination of local recurrence
38 Cytological examination with immunephenotyping, cytogenetics etc.
39 Cytological examination, uncertain if taken from primary tumour or metastasis
40 Surgical intervention without morphological examination
41 Autopsy without histological examination
46 Hormone receptor analysis
47 Molecular genetic analysis, PCR
57 Histological examination of local recurrence
60 Histological examination of metastasis
(68) Not coded - Histological examination of metastasis AND autopsy. Automatically given from a combination of basis 60 and 80/82
70 Histological examination of primary tumour

(71) Not coded - Automatically given from a combination of DS 5 and Basis 32, 33, 34, 35, 39, 70, 74, 75, 76
72 Clinical notification about histological examination
74 Histological examination with electron microscope (ultrastructural diagnostics)
75 Histological examination with immunephenotyping, flow-cytometri
76 Histological examination with cytogenetics, moleculargenetic examination
(78) Not coded - Histological examination of primary tumour AND autopsy. Automatically given from a combination of basis 70 and 68/80/82.
79 Histological examination, uncertain if taken from primary tumour or metastasis
80 Autopsy with histological examination
81 Casual finding at autopsy with histological examination
82 Partial autopsy
83 Clinical notification about autopsy
98 Biopsy without any tumour
90 Death certificate
99 Unknown basis of diagnostics
Increasing priority: 71, 47, 46, 45, 99, 98, 90, 00, 10, 20, 30, 29, 31, 40, 83, 41, 82, 80, 22, 36, 39, 37, 32, 38, 72, 60, 79, 57, 70, 68, 78, 74, 75, 76, 81.

N2 Norway, Stage at diagnosis

0 No metastasis
1 or A Metastasis to regional lymph nodes
2 or B Metastasis to distant lymph nodes
3 or B Metastasis to organ in the same part of the body as the primary tumour
4 or B Metastasis to organ in another part of the body than the primary tumour
5 or D Microscopic growth into neighbouring tissue
6 or D Macroscopic growth into neighbouring tissue
7 Metastasis found, but uncertain where primary tumour is located
8 or D Microscopically infiltrating tumour
9 Unknown metastasis

N3 Norway, Coding of treatment

00 = No surgery
01 = Biopsy
02 = Surgical exploration with or without biopsy
07 = Sentinel node
09 = Local ablative treatment with or without biopsy
10 = Surgical removal of tumour and parts of or the entire organ(s)
11 = Surgical removal of tumour only
12 = Surgical removal of lymph nodes
13 = Transvesical prostatectomy (suprapubic), transvesical resection of tumors in the urinary bladder
14 = Mastectomy without removal of lymph nodes (C50)
Cystoprostatectomy - removal of prostate and urinary bladder at the same time (C61, C67)
Hemithyreoidectomy (C73)
15 = Mastectomy with removal of lymph nodes
16 = Mastectomy - unknown if lymph nodes are removed

17 = Breast-conserving surgery without removal of lymph nodes
18 = Breast-conserving surgery with removal of lymph nodes
19 = Breast-conserving surgery, unknown if lymph nodes are removed
20 = Trans-urethal resection (TUR) Conisation.
21 = Therapeutic intervention directed at metastasis (old code, not in use)
25 = Mastectomy with removal of sentinel lymph node
26 = Mastectomy with removal of sentinel lymph node and removal of lymph nodes
28 = Breast-conserving surgery with removal of sentinel lymph node
29 = Breast-conserving surgery with removal of sentinel lymph node and removal of lymph nodes
30 = Anastamosis or draining operations creating a passage outside the tumor (old code, not in use)
35 = Re-excision
40 = Other palliative surgical intervention, not directed at primary tumor or metastasis (old code, not in use)
43 = Prostate cancer primarily hormonal treated and later recessed by trans-vesical intervention (old code, not in use)
50 = Prostate cancer primarily hormonal treated and later recessed by trans-urethal intervention (old code, not in use)
95 = Biopsy - not from primary tumor (f.ex. from metastasis)
96 = Cytology
97 = Therapeutic intervention directed at metastasis/palliative care
99 = Unknown surgery

Radiotherapy
0 = No
1 = Yes
2 = Gamma knife
3 = Radioactive iodine
4 = Brachytherapy
5 = Protontherapy
9 = Unknown

Hormone therapy
0 = No
1 = Yes
2 = Orchiectomy (C61)
3 = Yes ("Other hormone therapy")
4 = Surgical castration + other hormone therapy
5 = Radiological castration + other hormone therapy
6 = Other combinations of hormone therapy
9 = Unknown
Blank = Unknown

Chemotherapy
0 = No
1 = Yes
9 = Unknown

Blank = Unknown

Other treatment
0 = No
1 = Yes
2 = Bone marrow transplantation. High-dose treatment with autologous stem cell support (HMAS)
3 = Hyperthermia treatment
4 = Immune modulation therapy
9 = Unknown
N = No
Blank = Unknown

Web Table 6. Clinical Cancer Registries with national coverage, operated by the Norwegian Cancer Registry (May 2017).

Cancer type	National registration		Status
	Data from	National funding	
Operating (May 2017)			
Childhood cancer	1985	2013	Collecting additional clinical data
Prostate cancer	2004	2009	Collecting additional clinical data (from 2004) and pathology data (from 2009)
Colorectal cancer	2007	2009	Collecting additional clinical and pathology data
Skin melanoma	2008	2013	Collecting additional clinical and pathology data
Breast cancer	2009	2013	Collecting additional clinical and pathology data
Lymphomas and lymphoid leukaemias	2011	2013	Collecting additional clinical data
Ovarian cancer*	2012	2013	Collecting additional clinical and pathology data
Lung cancer	2013	2013	Collecting additional clinical and pathology data
Oesophagus and stomach cancer	2015	**	Collecting additional clinical data
Planned			
Haematological cancer		**	Additional parameters for clinical and pathology data established – not collecting data yet
Central nervous system cancer		**	Additional parameters for clinical and pathology data established – not collecting data yet
Testicular cancer		**	Additional parameters for clinical and pathology data established – not collecting data yet
Sarcoma		**	Additional parameters for clinical and pathology data established – not collecting data yet
Bladder and urinary tract cancer		***	Planning additional parameters

* Will be extended to include all gynaecological cancers. Cervix uteri is the first additional site, hopefully in 2018.

** Applied for national funding, but the establishment of new quality registries is currently stopped in order to evaluate the existing registries and discuss a better model of funding.

*** Not yet applied for funding.

Web Table 7. Swedish Clinical Cancer Registries with national coverage on information network for cancer (INCA) platform (April 2017).

Cancer site	National registration		Coordinating Cancer Centre[1]
	From	On INCA platform from	
Breast	2008	2008	Stockholm Gotland
Cervix/vagina[2]	2011	2011	West
Endometrium[2]	2010	2010	West
Central nervous system	1999	2009	North
Head and neck[3]	2008	2008	North
Pituitary gland	1991	2012	Stockholm Gotland
Colon	2007	2008	North
Leukaemia, acute[4]	2007	2007	South
Leukaemia, chronic lymphatic	2000	2007	Stockholm Gotland
Leukaemia, chronic myeloid	2002	2007	Uppsala Örebro
Lung	2008	2008	Uppsala Örebro
Liver/gallbladder	2008	2008	West
Lymphoma	2000	2007	South
Melanoma of the skin	2003	2009	South East
Multiple myeloma	2008	2008	West
Myelodysplastic neoplasms	2009	2009	Uppsala Örebro
Myeloproliferative neoplasms	2008	2008	Stockholm Gotland
Kidney	2005	2009	Stockholm Gotland
Oesophagus/stomach	2006	2007	North
Ovary[2]	2007	2008	West
Pancreas	2010	2010	South East
Penis	2000	2009	Uppsala Örebro
Prostate	1998	2007	Uppsala Örebro
Rectum	1995	2007	North

Testis	2009	2009	South
Thyroid	2013	2013	West
Urinary bladder	1997	2008	South
Vulva	2012	2012	West

[1] National responsibilities for coordination (general support, update, statistical output) of registers are shared between Regional Cancer Centres.

[2] Part of the clinical cancer register of Gynecological Oncology.

[3] From 2008 part of the clinical cancer register for head and neck cancer.

[4] Different set of variables for acute lymphatic and acute myeloid/unknown leukaemia.