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ORIGINAL ARTICLE

Data quality at the Icelandic Cancer Registry: Comparability, validity, timeliness and completeness

LARA GUDRUN SIGURDARDOTTIR[1,2], JON GUNNLAUGUR JONASSON[1,3], SIGRUN STEFANSDOTTIR[1], ANNA JONSDOTTIR[1], GUDRIDUR HELGA OLAFSDOTTIR[1], ELINBORG JONA OLAFSDOTTIR[1] & LAUFEY TRYGGVADOTTIR[1,3]

[1]*Icelandic Cancer Registry, Icelandic Cancer Society, Reykjavik, Iceland,* [2]*Centre of Public Health Sciences, University of Iceland, Reykjavik, Iceland, and* [3]*Faculty of Medicine, University of Iceland, Reykjavik, Iceland*

Abstract

Introduction. The nationwide Icelandic Cancer Registry (ICR) was established in 1954 and has been extensively used for research from the outset although formal quality assessment of the registry database has not previously been undertaken. In this paper we report the first formal evaluation of the comparability, validity, timeliness and completeness of the ICR. *Material and methods.* Data from the ICR for the period 1955–2009 (41 994 cancer diagnoses) were used, applying established quantitative and semi-quantitative methods. In order to evaluate the completeness of the ICR, record linkage was performed between the ICR and the population-based Hospital Discharge Registry to identify potential missing cases for tumour diagnoses in 2000 and 2001. *Results.* The registration is in accordance with internationally accepted standards. It has high validity, but random variation in rates is prominent in this small population. Record linkage with the Hospital Discharge Registry revealed that in addition to the 2459 cancers registered in 2000–2001, 21 cases were missing, indicating 99.15% completeness. Tumours of the central nervous system constituted 71%, and haematological malignancies 19% of these missing entries. *Discussion.* The ICR has high completeness, validity and timeliness and is comparable to the cancer registries of the other Nordic Countries. As cancer registries have many important roles, it is of great importance that their data are at all times as complete and valid as possible. Thus the ICR aims to constantly improve and update the data gathering process.

The Icelandic Cancer Registry (ICR) was established by the Icelandic Cancer Society in 1954 and has since 1955 published incidence figures covering the entire Icelandic population, which currently comes to 320 000 individuals. The registry attained legal substantiation in 2007 when a new Medical Director of Health Act was legislated, rendering the ICR one of the population-based health registries authorised by the Icelandic Directorate of Health and making cancer registration mandatory. The Icelandic Cancer Society continues to run the cancer registry in accordance with a contract between the Directorate of Health and the Icelandic Cancer Society.

The registry has been extensively used for research from the outset [1], which in turn has provided valuable feedback for the registry and helped to maintain high quality. However, a formal quality assessment of the registry database has not previously been undertaken. The comparability, validity, timeliness and completeness of the ICR are evaluated in this paper according to previously described guidelines by Parkin [2] and Bray [3] that in turn were built on the International Agency for Research on Cancer (IARC) Technical Report on the subject 'Comparability and quality control in cancer registration' published in 1994 [4].

Material and methods

Information registered at the Icelandic Cancer Registry

The aim of the ICR is to register all cancers diagnosed in Iceland with the highest possible completeness

Correspondence: L. Tryggvadottir, Icelandic Cancer Society, Icelandic Cancer Registry, Reykjavik, Iceland. Tel: +354 5401970. Fax: +354 5401910. E-mail: laufeyt@krabb.is

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and quality. The registry collects information in accordance with recommendations from the European Network of Cancer Registries (ENCR) [5] on all malignant and in situ neoplasms, plus non-malignant neoplasms of the central nervous system and bladder.

Patients are identified through the unique 10-digit personal number that is assigned to all newborns and people residing in Iceland. This number is invariably used for all contact of individuals with the health care system and thus provides an efficient and reliable means of tracking patients and prevents duplication of registered cases. The unique personal number was introduced in Iceland in 1953 when the Population Register was founded [6].

All Icelandic pathology and haematology laboratories constitute the main data source for the ICR. The pathology reports, which are usually received within two months of cancer diagnosis, can provide cytological, histological, haematological, or autopsy information. Less comprehensive sources are hospital departments and healthcare facilities in Iceland. Statistics Iceland provides information on all malignancies that are notified on death certificates, which are scrutinised by the ICR and new diagnoses added to the registry if the information is confirmed. Statistics Iceland further updates monthly the vital status (alive/dead) and residence (if emigrated/immigrated) of registered individuals and provides information on the underlying cause of death. Any incomplete information is ascertained by contact with the aforementioned institutions and consultants. At present, 60% of the registry data are captured in electronic format and the aim is to increase this proportion to 90% within the next three years.

The international standards used for classification and coding of neoplasms by the ICR, and the definitions of incidence date and multiple primaries are described in the Results section, under comparability.

In 2011, systematic collection of TNM pathological (or clinical if pathological staging is not available) staging information was initiated at the ICR for the major cancer sites. Less complete staging information for the same cancer sites that has been collected during the past few decades will be completed to the extent possible. The most recent TNM version is used, but in order to facilitate conversion to other TNM versions, basic information, such as nodal status and tumour size is also registered. The ICR has announced interest in collaboration with clinicians to make use of the Swedish INCA platform [7], a thorough documentation and registration of various clinical parameters of tumour diagnoses.

Comparability

The comparability of the ICR was addressed by describing the international standards used for classification and coding of neoplasms for the period 1955–2009 (41 994 cancer diagnoses in 38 562 individuals), and by the definitions of incidence date and multiple primaries, applied by the ICR. We also describe the number and proportion of cancer diagnoses obtained from autopsy reports in 2005–2009, which can be an indicator of incidental diagnoses (cancers detected in asymptomatic individuals).

Validity

We applied three groups of methods that provide numerical indications of validity [2,3]. First, relating to diagnostic criteria, we calculated the percentage of morphologically verified (MV%) tumours in 2005–2009, determined the proportion of cases

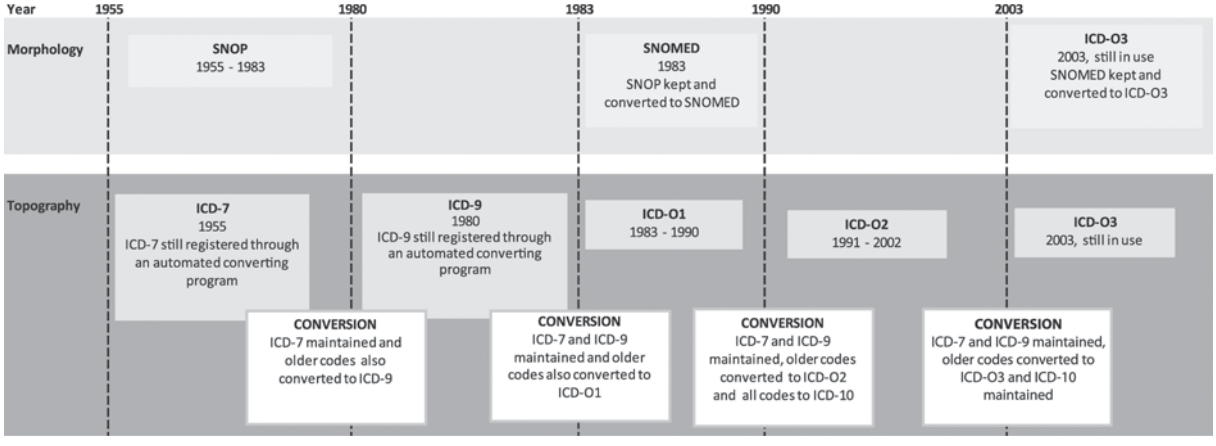

Figure 1. The standards of classification and coding of neoplasms, Iceland 1955–2009.

based on death certificate only (%DCO), compared the %DCO in Iceland with other European countries for the time period 1998–2002 [8], and presented the number and proportion of death certificate initiated (DCI) cases. Second, we describe how the ICR ensures internal consistency. Lastly, the magnitude of missing information was addressed by reporting the proportion of cases diagnosed in 2005–2009 with primary site uncertain (PSU) based on the ICD-10 diagnostic code C80 and comparing this measure with selected European registries for 1998–2002 [8].

Table I. Total number of cancer cases, average number of notifications per case, %MV, and %DCO, Iceland 2005–2009.

ICD-10[a]	Site	Cases	Notificat. per case	MV%[b]	%DCO[c]
C00–96	All sites	7071	1.8	96.4	0.2
C00	Lip	16	1.8	100.0	0
C01–02	Tongue	24	2.4	100.0	0
C03–06	Mouth, other	42	2.9	100.0	0
C07–08	Salivary glands	14	2.4	100.0	0
C09–14	Pharynx	22	2.1	100.0	0
C15	Oesophagus	94	1.7	97.9	0
C16	Stomach	159	1.7	98.1	0
C17	Small intestine	35	1.4	100.0	0
C18	Colon	525	1.8	97.2	0.6
C19–21	Rectum, rectosigmoid, anus	185	1.9	99.5	0.5
C22	Liver	58	1.5	67.0	0
C23–24	Gallbladder, bile ducts	45	1.5	89.0	0
C25	Pancreas	143	1.5	71.3	1.4
C30–31	Nose, sinuses	9	2.7	100.0	0
C32	Larynx, epiglottis	26	1.7	100.0	0
C33–34	Lung, trachea	780	1.7	94.1	0.4
C38	Mediastinum, pleura	2	1.0	100.0	0
C40–41	Bone	28	1.7	100.0	0
C43	Melanoma of the skin	254	1.5	100.0	0
C44	Skin, non-melanoma	332	1.6	100.0	0
C45	Mesothelioma	15	1.4	100.0	0
C46	Kaposi's sarcoma	16	1.1	100.0	0
C47	Autonomic nervous system	3	2.3	100.0	0
C48–49	Soft tissues	78	1.7	98.9	0
C50	Breast	1045	2.1	99.2	0
C53	Cervix uteri	69	1.5	100.0	0
C54	Corpus uteri	138	1.9	99.3	0.7
C56	Ovary	79	1.9	98.7	1.3
C51–52, C57	Other female genital	23	1.8	100.0	0
C61	Prostate	1107	1.9	98.1	0.3
C62	Testis	52	1.1	100.0	0
C60	Penis	14	1.8	100.0	0
C64	Kidney excluding renal pelvis	239	1.2	93.7	0
C65	Renal pelvis	19	1.6	94.7	0
C66–68	Bladder, ureter, urethra	339	2.0	99.7	0
C69	Eye	15	1.6	100.0	0
C70–72	Central nervous system	222	1.2	81.5	0
C73	Thyroid gland	138	1.7	99.3	0
C37, C74–75	Other endocrine glands	17	1.5	82.3	0
C80	Unspecified	151	1.8	84.8	0.7
C81	Hodgkin lymphoma	34	1.3	100.0	0
C82–85	Non-Hodgkin lymphoma	195	1.8	99.0	1.0
C88	Malignant immunoproliferative diseases	18	1.7	94.5	0
C90	Multiple myeloma	108	2.7	99.1	0.9
C91–95	Leukaemia	144	2.1	100.00	0

[a]ICD-10, international classification of disease, 10th version
[b]%MV, percent morphologically verified
[c]%DCO, percent death certificate only

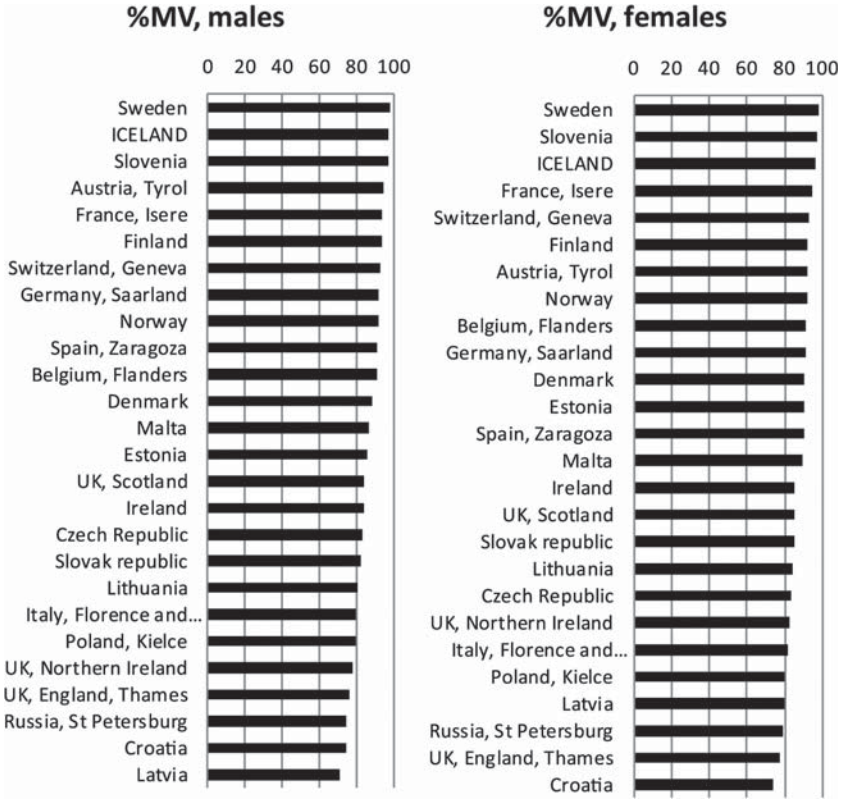

Figure 2. Percentage morphologically verified (%MV) cancer diagnoses: comparison of Iceland with selected European registries (1998–2002), all cancer sites combined, by gender [8].

Timeliness

We evaluated timeliness in terms of the median number of days from the diagnosis of cancer in 2007 to registration through 31 September 2011. We further calculated the proportion registered: (a) within one year; (b) 15 months from the end of 2007 when cancer incidence is reported on the Icelandic Cancer Registry's website [9]; and (c) within two years.

Completeness

The completeness of the ICR was addressed by applying three semi-quantitative methods and one quantitative method [2]. First, we used historic data methods by examining the stability of incidence trends over the period 1955–2009, and by comparing the age-specific incidence rates of childhood cancer in 2000–2009 with the corresponding reference intervals based on published deciles for childhood cancer [8]. To minimise the effect of random variation for childhood cancer incidence in the small Icelandic population, we used a period of ten years instead of five years. Second, the mortality:incidence ratios (2005–2009) are compared with "1 minus 5-year relative survival" probabilities based on diagnoses in 2001–2005. Third, the number of sources/notifications per case for 2005–2009 are listed.

Of the quantitative methods outlined by Parkin and Bray we applied the independent case ascertainment method, searching in the ICR for diagnoses registered in the population-based Hospital Discharge Registry. The Hospital Discharge Registry that was established in 1999 is a population-based electronic registry covering the diagnoses of all hospitalised patients in Iceland, currently coded according to the International Classification of Diseases 10th Revision (ICD-10). In the year 2005 the ICR received data files on all hospital discharge tumour diagnoses in 2000 and 2001. The comparison with the Hospital Discharge Registry included all tumours recommended by the ENCR to be included in cancer registries. We used ICD-10 codes for the record linkage for all cancers (all C codes) as well as certain benign neoplasms, such as of the central nervous system and myelodysplastic syndromes (selected codes; D30, D32–33, D35, D41–48). All tumours belonging to these categories were extracted from the Hospital Discharge Registry and searched for in the ICR using the personal identification number. Every potential new entry

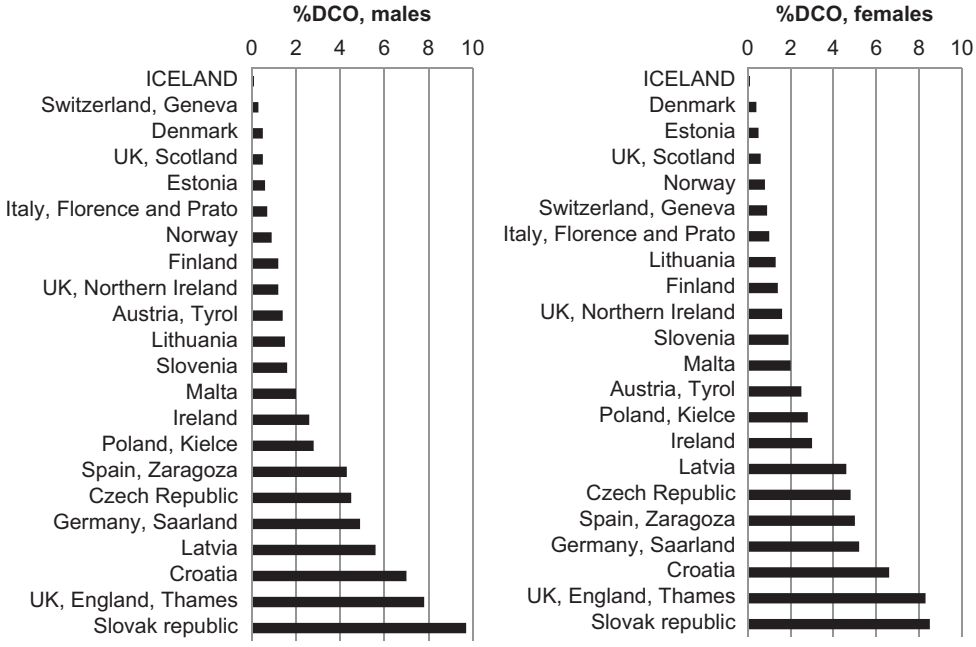

Figure 3. Percentage death certificate only (%DCO) cancer diagnoses: comparison of Iceland with selected European registries (1998–2002), all cancer sites combined, by gender [8].

was scrutinised by reviewing medical records from hospitals and archives. New entries were added to the ICR if the information was confirmed. If a diagnosis was uncertain, a final decision was made by a pathologist (the medical director of the ICR).

Ethical approval

The study protocol was approved by the Icelandic Ethical Review Board and the Icelandic Data Protection Authority.

Results

Comparability

The ICR has since 2003 coded all malignancies and in situ neoplasms according to ICD-O-3 [10] and has also by conversion kept ICD-7 and ICD-9 codes. Furthermore, all topography codes have been converted to ICD-10 codes for the purpose of reporting and communication. Figure 1 shows an overview of the international standards from the World Health Organization [11], used by the ICR.

The registration of incidence date at the ICR is according to the ENCR recommendations based upon a hierarchy of possible sources [5] and the registration of multiple primary tumours is also based on the ENCR recommendations. According to published figures for the years 2005–2009 the number of second or higher order primaries was 1129, which was 16% of all diagnoses.

For the purpose of local research, the ICR also keeps more detailed information on malignancies originating in ipsilateral or contralateral organ or tissue, where an additional tumour is classified as a new primary or a recurrent one according to a clinicopathologic analysis.

Of cancers diagnosed in the years 2005–2009 (all sites), 0.6% were incidentally diagnosed at autopsy. Of the three cancer sites that constituted half of all these diagnoses, prostate, thyroid and kidney, the proportion detected at autopsy for each site was 0.7%, 4.3% and 2.6%, respectively.

Validity

Of all registered cancers in 2005–2009, 96.4% were morphologically verified (%MV) (Table I). The proportion was lowest for liver (67.0%) and pancreas (71.3%). The proportion of registrations obtained from death certificates only (%DCO) for all sites combined was 0.2% (Table I). Cancers of the pancreas and ovaries had the highest proportion, or 1.4% and 1.3%, respectively. When Iceland was compared with selected European countries [8], the %MV was among the highest (Figure 2) and %DCO was lowest for both genders (Figure 3). The proportion of cancers first registered on the basis of death certificates (DCI) was on average 4.4%, whereas the proportion remaining after checking (DCO) was 0.3% (Table II).

Table II. Number and proportion of DCI and DCO registrations, Iceland 2005–2009.

Year	DCI[a] (%)	DCO[b] (%)	Total number of cancers registered
2005	53 (4.0)	5 (0.4)	1327
2006	39 (2.8)	3 (0.2)	1417
2007	77 (5.4)	2 (0.1)	1423
2008	62 (4.2)	5 (0.3)	1465
2009	78 (5.4)	3 (0.2)	1439
Total	309 (4.4)	18 (0.3)	7071

[a]DCI, death certificate initiated
[b]DCO, death certificate only

The proportion of cancers registered with primary site uncertain (PSU) was 1.9% for men and 3.1% for women. The proportion increased with advancing age and was very low among the youngest age group (0–44 years) with only two PSU diagnoses of 666 cancers (data not shown). When compared with selected European countries [8] the ICR had a slightly lower proportion of PSU than the other Nordic countries (Figure 4).

For internal consistency, the ICR uses a local programme for data entry. When all data have been entered, the IARC/IACR check programme is applied. All new notifications are checked before they are entered and discrepancies are further looked into. Whenever new information is received on a previously registered case, the registration is corrected accordingly.

Timeliness

The median time from date of diagnosis in 2007 to registration at the ICR was 238 days (range 49–1445 days). The majority of cancers diagnosed in 2007 (84.8%) were available at the ICR for research purposes within one year from the registration year, and 94.8% at the time of incidence publication on the website of the cancer registry, which is currently 15 months. Within two years, 96.9% of registrations had been listed as incident cases at the registry.

Completeness

The gender-specific incidence time trends for all cancers (except non-melanoma skin cancer) and selected sites are shown in Figure 5. The trends were stable, although random variation due to the small population size is apparent.

For the age- and gender-specific incidence rates for childhood cancer (all types combined) during the period 2001–2009, the rate for boys aged 10–14 years was above the upper limit of the reference interval given by Parkin et al. [12]. All other rates were within the reference rates.

The mortality: incidence (M:I) ratio did not deviate strongly from (1-survival) (Figure 6). For liver cancer, the M:I ratio was higher than (1-survival) for females, but lower for males. A reasonable coherence in M:I ratios is observed between Iceland (2005–2009) and Norway (2004–2008) (Figure 7) [13].

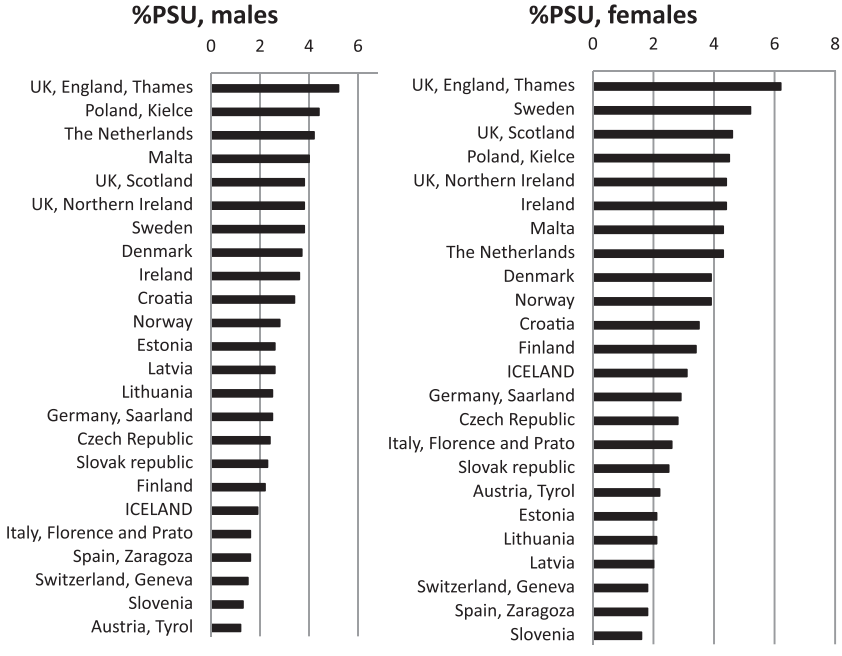

Figure 4. Percentage primary site uncertain (%PSU): comparison of Iceland with selected European registries (1998–2002), all cancer sites combined, by gender [8].

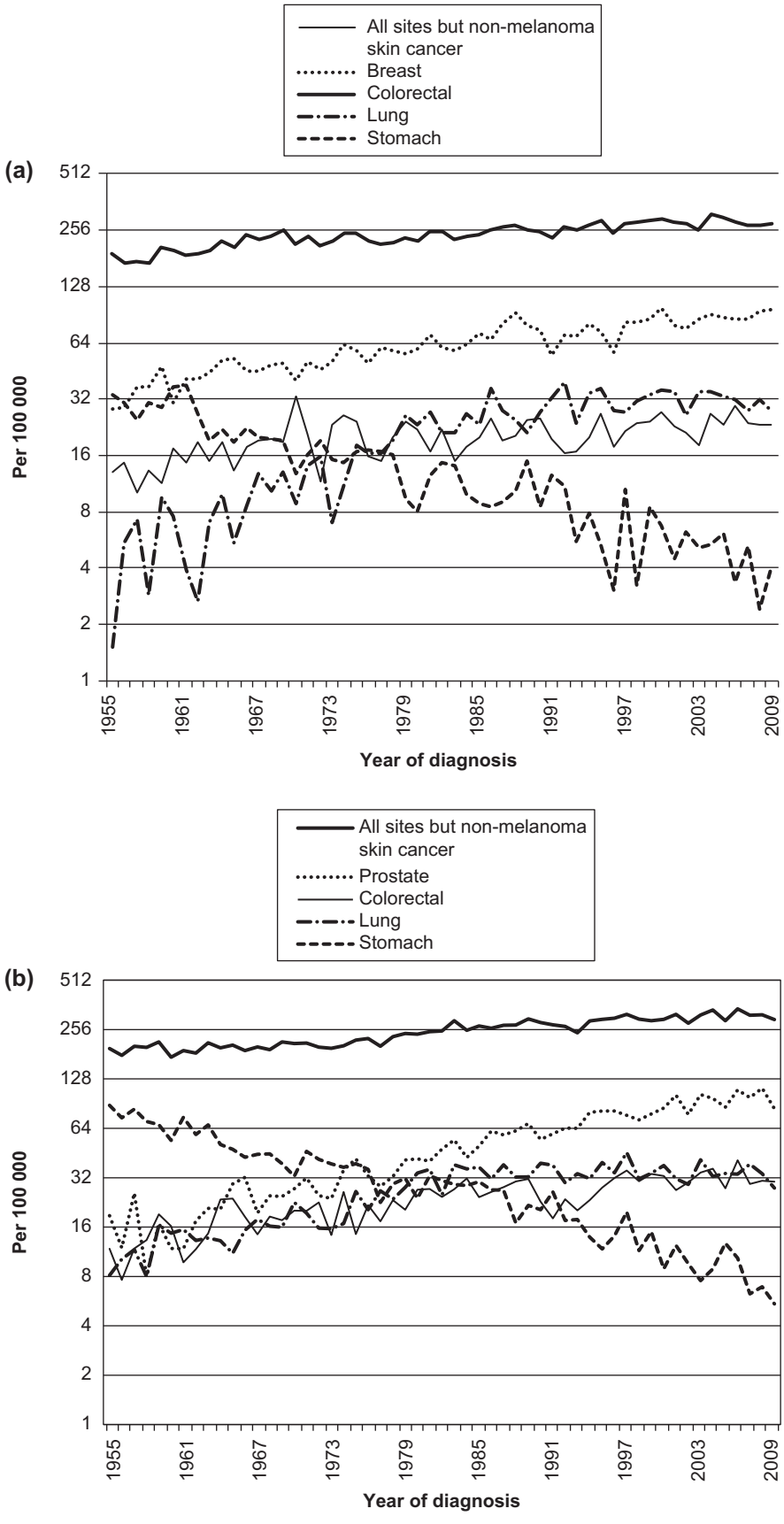

Figure 5. (a) Annual trends in age-standardised (world) incidence rates for all sites combined and for selected sites, Iceland 1955–2009, females. (b) Annual trends in age-standardised (world) cancer incidence rates for all sites combined and for selected sites, Iceland 1955–2009, males.

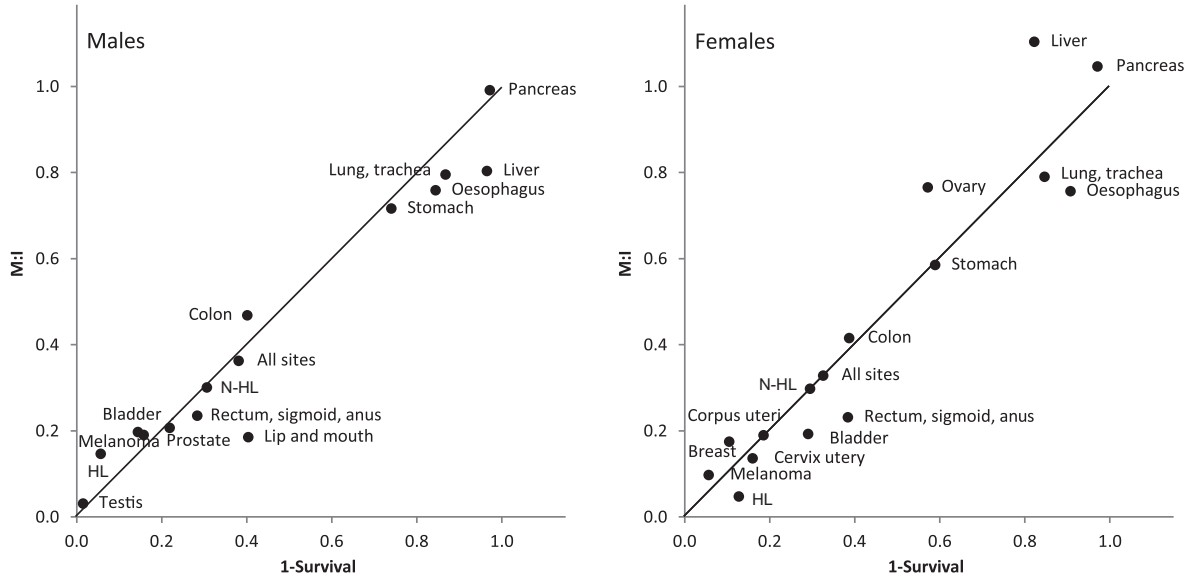

Figure 6. Mortality:incidence ratios* (2005–2009) versus 1-survival (2001–2005), Iceland. *"Melanoma" refers to melanoma of the skin; "Bladder" refers to bladder, ureters and urethra; "HL" refers to Hodgkin lymphoma and "N-HL" refers to Non-Hodgkin lymphoma.

The average number of notifications per case for all sites combined was 1.8 (Table I). Multiple myeloma and cancers of the head and neck had the highest number of notifications, whereas cancers of the testis, kidney and the central nervous system were among the sites with the fewest notifications per case.

With the independent case ascertainment (Hospital Discharge Registry record linkage), we identified 132 potential missing cases. However, the majority (80.3%) of these had either already come to the attention of the ICR and were not eligible for inclusion in the registry, or had been wrongly coded in the Hospital Discharge Registry. The remaining 21 verified missing cases for the relevant two-year period (2000–2001) were added to the 2459 registrations (0.85% of total). Hence, according to this linkage, the estimated completeness is 99.15%. Tumours of the central nervous system (71%) and haematological malignancies (19%) constituted 90% of all missing entries (Table III). Finally, five additional tumours diagnosed before 2000–2001 were added to the ICR.

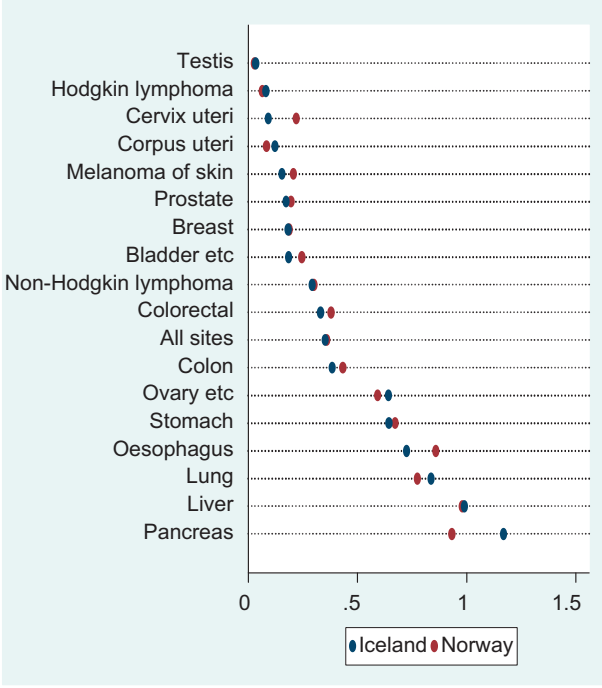

Figure 7. Comparison of mortality:incidence ratios between (2005–2009) and (2004–2008), by cancer site [13].

Discussion

This first formal quality study of the nationwide Icelandic Cancer Registry confirmed high validity and completeness. The circumstances in Iceland are favourable due to a good health care system, a tradition of thorough record keeping, nationwide pathology databases and the state personal identification number, which is invariably recorded whenever an individual receives health service.

Overall, data from the ICR appear to be reasonably comparable to data from other cancer registries and the coding and classification procedures of the ICR adhere to agreed international guidelines [5]. The same applies to the rules for assigning incidence date and multiple primaries. The proportion of second or higher order primaries (16%) is similar to that in Sweden (18%) [14]. Comparability can be compromised when screening

Table III. Unregistered tumour diagnoses (2000–2001) added to the ICR after searching in the Hospital Discharge Registry.

Cancer type (ICD 10)	Number of new tumours	Total number in ICR	Percentage (%)
Prostate (C61)	1	363	0.3
Meninges (C70/D32)	8	21	38.1
Brain (C71/ D33/D43)	2	58	3.4
Spinal cord (C72)...CNS	2	2	100.0
Pituitary gland (C75/D35)	3	12	25.0
Multiple myeloma (C90)	1	20	5.0
Lymphoid leukemia (C91)	1	36	2.8
Myeloid leukaemia (C92)	2	18	11.1
Unknown primary (C80)	1	37	2.7

is introduced in a nation or if screening techniques differ between countries [3]. As for screening in Iceland, the Cancer Detection Clinic initiated nationwide organised screening for cervical cancer in 1964 and for breast cancer in late 1987 [15]. Comparability can also be affected by autopsy rates. In Iceland the autopsy rate has decreased over the last few decades with a current very low proportion of 0.6%.

The proportion of morphologically verified cases was high (96.4%) and such a high proportion might in some instances be explained by too much reliance on pathological diagnoses [3]. However, a more likely explanation is that the level of diagnostic activity is high in Iceland, reflected by a relatively large proportion of cancer patients undergoing biopsies. Similarly, the low proportion of cancers identified through death certificates only (0.3%) can be explained by an effective search in this small population for further information for cancers first identified through death certificates (DCI). Another contributing factor for the low DCO% could be the low autopsy rate.

The proportion of cancers with primary site uncertain was low (1.9%) and most prevalent in the oldest age groups, as is expected. This proportion was comparable with the other Nordic countries.

The median time from diagnosis to availability for research is eight months (238 days) and the ICR collects, processes and reports relatively reliable and complete cancer data within 15 months, which is within the recommended guidelines [16]. However, it should be possible to improve timeliness further, as an increasing proportion of data is captured electronically and also because of facilitation of the registration process by recent direct electronic access of the ICR to the electronic hospital record database at the University Hospital.

The semi-quantitative methods mainly indicated a high degree of completeness. The incidence rates have been stable over time and comparable to the other Nordic countries, the incidence rates for childhood cancers were not below the given reference range and the M:I ratio was for the most part approximated by a (1-survival) probability of five years. The M:I ratio for liver and pancreas cancer for females was larger than 1, which could be an indication of incompleteness in incidence. However, this observation was confined to females, indicating random variation as the explanation, which is to be expected in this small population. This interpretation was supported by studying previous diagnostic years (data not shown), where there were great fluctuations in the M:I ratios for these cancers. On the other hand, the number of notifications per case was on average 1.8 for all sites combined, which was relatively low compared to the Norwegian Cancer Registry [17].

The independent case ascertainment also pointed to very high completeness, or 99.15%, which is at a similar level as in the other Nordic cancer registries [17–20]. The Hospital Discharge Registry had not been used as a data source for the ICR before this record linkage took place and was therefore an independent data source. Most of the missing tumours were neoplasms of the central nervous system or haematological malignancies and the registry has now taken up yearly record linkage with the Hospital Discharge Registry to search for these two types of malignancies.

Cancer registry data make it possible to describe the size and dynamics of the cancer burden, to study cancer etiology, evaluate the effects of primary and secondary prevention and to plan health services. They have thus great relevance for public health and must be at all times as complete and valid as possible.

Conclusion

The ICR was found to have very high completeness and quality. This is due to many factors, including the application of a rigorous set of procedures at the registry, a well-functioning health care system, a unique personal identification number, and a

close collaboration with the Icelandic pathology departments as well as with the other Nordic cancer registries.

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Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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