CHAPTER 3 The editorial process

The purpose of this volume is to present incidence rates for various types of cancer from the population-based cancer registries of sub-Saharan Africa. The participating registries are all members of the African Cancer Registry Network (AFCRN); therefore, their data meet the minimum quality criteria required for AFCRN membership. Specifically, member registries must collect information on at least 50% of the cancer cases in their target population, and must achieve at least 70% coverage within 3 years of joining AFCRN (http://afcrn.org/membership/membership-criteria/).

However, the quality of the data from these registries is not necessarily consistent from one year to the next, nor is the completeness (or validity) of the data across the different types of cancers. Therefore, in order to present incidence rates that are reasonably comparable, we submitted the datasets to an editorial process that enabled us to (1) decide for which period (i.e. for which years) the data should be presented and (2) establish an indication of the probable data quality.

The methods used in this editorial process are described below, and the results of these evaluations are incorporated into the *Notes* sections within the descriptions of the overall results by registry in Chapter 4 (p. 13). The results are also presented in the data quality indicators tables (Chapter 5, p. 114), which list the values (by anatomical site, covered population, and sex) for two key indicators: the percentage of cases that were microscopically verified (MV%) and the percentage of death-certificate-only cases (DCO%), i.e. cases for which no information source other than a death certificate mentioning cancer could be found.

ELEMENTS OF THE EVALUATION

The practical aspects of evaluating the quality of cancer registry data, along with the techniques used to do so, have been examined in a two-part review (Bray & Parkin, 2009; Parkin & Bray, 2009). They are also described briefly, in the context of low- and middle-income settings, in the recent IARC Technical Publication No. 43: Planning and developing population-based cancer registration in low- and middle-income settings (Bray et al., 2014).

The editors of the present volume evaluated the completeness and validity of each registry's contributed data using a specially designed set of editorial tables, based on those used in IARC's Cancer Incidence in Five Continents (CI5) series.

Stability of the incidence rates over time: Editorial table 1

Changes in the completeness of registry data from year to year may lead to the appearance of unexpected or implausible incidence trends within a registry's dataset. Therefore, one of the key editorial tables (Editorial table 1, p. 8) lists the number of new cases registered by anatomical site per calendar year and the corresponding percentage of the total number of cases, broken down by sex. The average numbers of cases registered per month are listed at the bottom of the "Both sexes" section of the table, with an accompanying bar chart that provides a visual check of the amount of variation in the total numbers of cases registered each month (at all anatomical sites and in both sexes) over the time period covered. In some cases, this visual check may suggest potential problems with the registration process (or the source population data) during the registration period.

The choice of years to be included in the main analysis for each registry was based on the information in Editorial table 1. Therefore, a more limited time period appears in the subsequent editorial tables and in the final table of incidence that accompanies each registry's entry in Chapter 4.

Annual incidence by age group: Editorial table 2

Editorial table 2 (p. 9), which is generated separately for males and females, presents average annual incidence rates (per 100 000 person-years) by anatomical site and patient age group, as well as summary rates for the time period selected on the basis of Editorial table 1.

For each site listed, the table also shows the number of registered cases with unknown patient age (Age unk) and the percentage of registered cases that were microscopically verified (MV%).

The definition of microscopically verified cases includes histologically confirmed cases, cases diagnosed on the basis of exfoliative cytology specimens, and cases of leukaemia diagnosed on the basis of haematological examination (without examination of bone marrow). The main use of MV% as an indicator of data quality is as a measure of validity; however, a very high proportion of cases diagnosed by histology, cytology, or haematology - higher than might reasonably be expected - may also suggest that a registry is overreliant on pathology laboratories as sources of information and is therefore failing to find cases diagnosed by other means. MV% values are also presented in Editorial table 4 (p. 11), where observed values that are significantly different than expected for the region are flagged. See the section on Editorial table 4 for more details.

At the foot of Editorial table 2 is a set of reference values for incidence rates (all sites) in the childhood age groups (0–4 years, 5–9 years, and 10–14 years), derived from the data of Volume X of CI5. These reference values are included for the purpose of comparison with the corresponding observed rates presented in the table, in order to investigate

the possibility of underenumeration or duplicate registration within the data pertaining to paediatric cases. In general, the overall incidence rates of all types of cancers combined tend to be much less variable in children than in adults, although there are some well-documented geographical and ethnic differences for certain childhood cancers.

Age-specific incidence curves: Editorial table 3

Editorial table 3 (p. 10) shows a set of age-specific incidence curves for 12 anatomical sites by sex. These curves were examined to detect any abnormal fluctuations in the anticipated patterns, such as an unexpected drop in the rate of increase in incidence in older age groups, which may be indicative of underascertainment within these groups (although there can also be other explanations). These curves can also reveal problems with the source files used to determine the size of the populations at risk in the various age groups.

Comparison of observed versus expected values: Editorial table 4

The main purpose of Editorial table 4 (p. 11) is to investigate the possibility of incomplete registration by comparing observed incidence rates with expected values (reference values) calculated using data from registries in the same region. The table presents the observed age-standardized incidence rates (ASRs) and their standard errors for cancers occurring at 22 anatomical sites (and the total for all sites) in males and females, along with the ratio of the observed value to the expected value (O/E). If an observed ASR is significantly different from the reference value for the region, the ASR and the O/E are shown in bold, and the ASR is flagged with a greater-than symbol (>) if the value is higher than expected or a less-than symbol (<) if the value is lower than expected. The statistical test used for this comparison is described in Volume VIII of CI5 (Parkin & Plummer, 2002). The ASRs used as reference values for comparison are the estimated average rates reported in GLOBOCAN 2012 (Ferlay et al., 2013) for the same region of Africa (eastern, central, southern, or western). In some cases, deviation from regional reference values may be a result of true local variations in the prevalence and distribution of risk factors, or in the presence or intensity of screening for certain cancers, but systematic discrepancies (i.e. those seen consistently across several different anatomical sites) suggest the possibility of underregistration (or overregistration, e.g. due to the inclusion of duplicate records)

The percentage of registered cases that were microscopically verified (MV%) is also shown in Editorial table 4, with any observed value that is significantly greater than or less than the expected value marked in bold and flagged with a greater-than symbol (>) or a less-than symbol (<), respectively. The reference MV% values used for this comparison are the mean observed values from 14 cancer registries in sub-Saharan Africa (listed in the table's footnotes). The statistical test used for this comparison is described in Parkin & Plummer (2002).

For the registries with access to death certificates as a source of information on new cancer cases, Editorial table 4 also lists the percentage of death-certificateonly cases (DCO%): cases for which no information source (i.e. hospital or pathology records) other than a death certificate mentioning cancer could be found. As indicated in the subsections of Chapter 4 (p. 13) that discuss the individual registry results, only a few of the participating registries use death certificates to identify new cancer cases, and of those that do, not all include death-certificate-only cases in their databases. A high DCO% may indicate incomplete registration, since it could be a result of cancer cases not being registered before patients die. However, DCO% values must be interpreted in the context of the local circumstances. In some countries, the quality of death certificates can be very poor, with many deaths erroneously attributed to cancer, and registries may have difficulty tracing these cases back to a hospital capable of confirming (or contradicting) the information on the death certificate.

The population pyramid: Editorial table 5

Editorial table 5 (p. 12) uses a population pyramid to illustrate the population at risk (usually the average annual person-years) during the period selected for analysis. The nature of the estimates and the sources of the population data are described in a footnote below the pyramid.

MORTALITY-TO-INCIDENCE (M:I) RATIOS

M:I ratios are an important indicator of completeness, and their use for this purpose is an example of the independent case ascertainment method of evaluating registry completeness (Parkin & Bray, 2009). An M:I ratio compares the number of deaths due to a specific type of cancer over a specific period of time (obtained from a source that is independent of the registry – usually the vital statistics system) with the number of new cases of that type of cancer registered during the same period. When the quality of the mortality data is good (especially in terms of the accuracy of cause of death) and incidence and survival are in steady state, the M:I ratio is approximated by 1 minus the 5-year survival probability.

Very few countries in sub-Saharan Africa have comprehensive registration of death with cause of death medically certified. For the four countries that do – Mauritius, France (Réunion), Seychelles, and South Africa – we include tables listing the numbers of deaths due to cancer and the M:I ratios (expressed as percentages) by anatomical site. These tables are included in the subsections of Chapter 4 (p. 13) that discuss the individual registry results.

M:I ratios that are higher than expected raise suspicion of incompleteness (i.e. incident cancers missed by the registry), especially if the values are high for several different sites. However, under- or overreporting of tumours on the death certificates distorts this relationship, as does a lack of constancy in incidence and case fatality (the rate of death among incident cases) over time. In none of the four countries mentioned above is death registration considered to be of high quality (Mathers et al., 2005), and in South Africa it is considered to be of low quality. Nevertheless, the tables may give an indication of completeness when the M:I ratios are compared with those estimated for the same geographical region reported in GLOBOCAN 2012 (Ferlay et al., 2013).

Editorial table 1. Stability of the incidence rates (the number of new cases) over time

Registry X (2003-2012)

mher of cases in major diagnosis groups in single calendar years of observation

		Nui	Number of cases in	in major diagnosis groups in	osis groups in s	single calendar years of observation	years of observ	vation				
Site	2003	2004	2005	2006	Males 2007	2008	2009	2010	2011	2012	Total	EAPC
Lip, oral cavity, and pharynx (C00–14) Digestive organs (C15–26) Respiratory organs (C30–39)	12 (5.6) 39 (18.1) 15 (6.9)	20 (6.3) 64 (20.3) 17 (5.4)	12 (4.3) 65 (23.0) 21 (7.4)	21 (5.5) 91 (23.8) 23 (6.0)	14 (3.4) 95 (23.2) 29 (7.1)	25 (6.4) 92 (23.5) 29 (7.4)	13 (3.6) 87 (23.8) 29 (7.9)	9 (3.2) 68 (23.9) 13 (4.6)	14 (5.6) 63 (25.1) 16 (6.4)	7 (3.0) 62 (26.2) 17 (7.2)	147 (4.7) 726 (23.2) 209 (6.7)	-5.68 -0.53 -0.60
Bone, carmage, metanoma (C40-45) Kaposi sarcoma (C46) Male genital organs (C60-63)	1 (0.5) 84 (38.9)	2 (0.6) 112 (35.6)		0 (0.0) 0 (0.0) 115 (30.0)	2 (0.5) 125 (30.6)	10 (28.1)	5 (1.4) 96 (26.3)	3 (1.1) 94 (33.1)	2 (0.8) 75 (29.9)	3 (2.1) 3 (1.3) 67 (28.3)	22 (0.7) 982 (31.3)	-3.58
Urinary organs (C64–68) Eye, brain, thyroid etc. (C69–75) Haematonoietic tissues (C81–96)	9 (4.2) 6 (2.8) 26 (12.0)	18 (5.7) 12 (3.8) 38 (12.1)	6 (2.1) 18 (6.4) 29 (10.3)	8 (2.1) 22 (5.7) 49 (12.8)	16 (3.9) 25 (6.1) 49 (12.0)	11 (2.8) 25 (6.4) 50 (12.8)	11 (3.0) 13 (3.6) 59 (16.2)	9 (3.2) 12 (4.2) 47 (16.5)	6 (2.4) 9 (3.6) 43 (17.1)	10 (4.2) 15 (6.3) 33 (13.9)	104 (3.3) 157 (5.0) 423 (13.5)	-2.47 1.61 3.70
Other and unspecified All sites except skin (C00–96 exc. C44)	17 (7.9) 216 (100.0)	24 (7.6) 315 (100.0)	19 (6.7) 282 (100.0)	35 (9.1) 383 (100.0)	35 (8.6) 409 (100.0)	29 (7.4) 391 (100.0)	37 (10.1)	23 (8.1)	19 (7.6) 251 (100.0)	18 (7.6)	256 (8.2) 3133 (100.0)	-0.11
Site	2003	2004	2005	2006		2008	2009	2010	2011	2012	Total	EAPC
Lip, oral cavity, and pharynx (C00–14) Digestive organs (C15–26) Respiratory organs (C30–39) Bone, cartilage, melanoma (C40–43) Kaposi sarcoma (C46)	7 (1.9) 39 (10.5) 9 (2.4) 9 (2.4) 0 (0.0)	13 (2.8) 39 (8.4) 8 (1.7) 7 (1.5) 1 (0.2)	12 (2.5) 42 (8.8) 9 (1.9) 5 (1.0) 0 (0.0)	9 (1.7) 49 (9.4) 13 (2.5) 24 (4.6) 0 (0.0)		8 (1.4) 59 (10.4) 19 (3.4) 18 (3.2) 3 (0.5)	10 (1.8) 66 (12.0) 15 (2.7) 8 (1.5) 4 (0.7)	8 (1.6) 45 (9.0) 11 (2.2) 11 (2.2) 2 (0.4)	13 (3.6) 41 (11.2) 9 (2.5) 7 (1.9) 1 (0.3)	3 (0.8) 48 (12.6) 8 (2.1) 8 (2.1) 1 (0.3)	100 (2.1) 471 (9.9) 114 (2.4) 110 (2.3) 12 (0.3)	-5.93 2.31 0.96 -0.05
Female geniral organs (C51–58) Urinary organs (C64–68) Eye, brain, thyroid etc. (C69–75) Haematopoietic tissues (C81–96) Other and unspecified	128 (345) 10 (2.7) 13 (3.5) 13 (3.5) 6 (1.6) 371 (100.0)	146 (3.1.2) 8 (1.7) 8 (1.7) 23 (4.9) 16 (3.4) 465 (100.0)	170 (35.5) 10 (2.1) 20 (4.2) 30 (6.3) 15 (3.1) 478 (100.0)	165 (3.1.6) 8 (1.5) 22 (4.2) 37 (7.1) 14 (2.7) 522 (100.0)	189 (353) 8 (15) 27 (50) 34 (63) 18 (34) 536 (100,0)	145 (25.6) 6 (1.1) 42 (7.4) 37 (6.5) 39 (6.9) 567 (100.0)	142 (25.8) 10 (1.8) 26 (4.7) 29 (5.3) 40 (7.3) 551 (100.0)	147 (29.3) 11 (2.2) 18 (3.6) 29 (5.8) 15 (3.0) 501 (100.0)	93 (25.9) 93 (25.4) 4 (1.1) 15 (4.1) 23 (6.3) 18 (4.9) 366 (100.0)	107 (28.2) 5 (1.3) 15 (3.9) 26 (6.8) 12 (3.2) 380 (100.0)	28 (3.2) 206 (4.3) 28 (1.7) 28 (4.3) 28 (5.9) 193 (4.1) 4737 (100.0)	3.34 6.88 6.88 1.61
Site	2003	2004		2006		s 2008	2009	2010	2011	2012	Total	EAPC
Lip, oral cavity, and pharynx (C00–14) Digestive organs (C15–26) Respiratory organs (C30–39) Bone, cartilage, melanoma (C40–43)	19 (3.2) 78 (13.3) 24 (4.1) 16 (2.7)	33 (4.2) 103 (13.2) 25 (3.2) 15 (1.9)	24 (3.2) 107 (14.1) 30 (3.9) 13 (1.7)	30 (3.3) 140 (15.5) 36 (4.0) 43 (4.8)	31 (3.3) 138 (14.6) 42 (4.4) 32 (3.4)	33 (3.4) 151 (15.8) 48 (5.0) 34 (3.5)	23 (2.5) 153 (16.7) 44 (4.8) 23 (2.5)	17 (2.2) 113 (14.4) 24 (3.1) 17 (2.2)	27 (4.4) 104 (16.9) 25 (4.1) 11 (1.8)	10 (1.6) 110 (17.8) 25 (4.1) 13 (2.1)	247 (3.1) 1197 (15.2) 323 (4.1) 217 (2.8)	-5.68 2.32 -0.01 -2.70
Kaposi sarcoma (C46) Breast (C50) Female genital organs (C51–58) Male conital organs (C61–53)	1 (0.2) 137 (23.3) 128 (21.8) 84 (14.3)	3 (0.4) 196 (25.1) 146 (18.7) 112 (14.4)		0 (0.0) 181 (20.0) 165 (18.2)	2 (0.2) 174 (18.4) 189 (20.0) 125 (13.2)	7 (0.7) 191 (19.9) 145 (15.1)	9 (1.0) 201 (21.9) 142 (15.5) 96 (10.5)	5 (0.6) 204 (26.0) 147 (18.7) 94 (12.0)	3 (0.5) 142 (23.0) 93 (15.1) 75 (12.2)	4 (0.6) 147 (23.8) 107 (17.3) 67 (10.0)	34 (0.4) 1738 (22.1) 1432 (18.2) 982 (12.5)	-0.09 -3.69
Unitary organs (C64-68) Eye, brain, thyroid etc. (C69-75) Haematopoleite its sues (C81-96) Other and unsvecified	19 (3.2) 19 (3.2) 39 (6.6) 23 (3.9)	26 (3:3) 20 (2:6) 61 (7:8) 40 (5:1)	16 (2.1) 38 (5.0) 59 (7.8) 34 (4.5)	16 (1.8) 16 (1.8) 44 (4.9) 86 (9.5) 49 (5.4)	24 (2.5) 24 (2.5) 83 (8.8) 83 (8.8) 83 (8.8)	17 (1.8) 17 (1.8) 67 (7.0) 87 (9.1) 68 (7.1)	21 (2.3) 39 (4.3) 88 (9.6) 77 (8.4)	20 (2.5) 30 (3.8) 76 (9.7) 38 (4.8)	10 (1.6) 24 (3.9) 66 (10.7) 37 (6.0)	15 (2.4) 30 (4.9) 59 (9.6) 30 (4.9)	184 (2.3) 363 (4.6) 704 (8.9) 449 (5.7)	2.51 3.49 2.46
All sites except skin (C00–96 exc. C44) Average registrations per month	587 (100.0) 49	780 (100.0) 65	760 (100.0) 63	905 (100.0) 75	945 (958 (100.0) 80	916 (100.0) 76	785 (100.0) 65	617 (100.0) 51	617 (100.0) 51	7870 (100.0)	-0.59
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Editorial table 2. Annual incidence by age group

Registry X (2006-2009)

Annual incidence per 100 000 person-years by age group: males

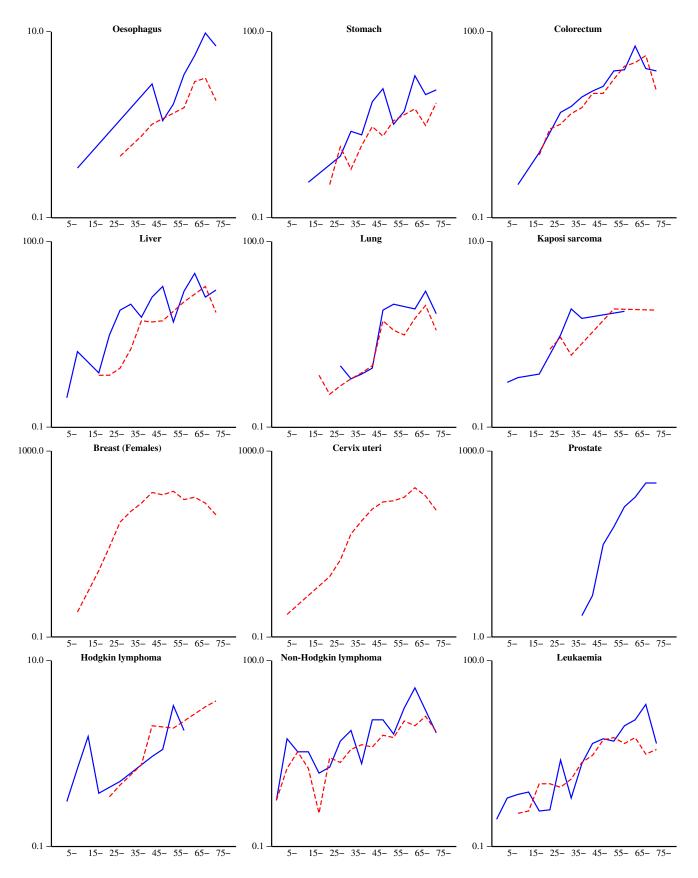
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Myeloid leukaemia	25	0	1 6	0.3	0.3	0.4	0.4																
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Reference values for incidence rates (all sites), per 100 000 person-years: age 0-4 years: < 10.4; age 5-9 years: < 13.0; age 10-14 years: < 15.4. For definitions and explanations of the terms and abbreviations used in this table, see the corresponding text in Chapter 2: Processing and presentation of the data (p. 3).

Editorial table 3. Age-specific incidence (per 100 000 person-years) curves for major diagnosis groups in males (solid blue lines) and females (dashed red lines)

Registry X (2006-2009)

Age-specific rates graphs for major diagnosis groups



Editorial table 4. Comparison of observed values versus expected (reference) values from registries in the same region

Registry X (2006-2009)

International comparison

		Males				
Site	Cases	ASR (se)	O/E	MV%	DCO%	ICD-10
Lip, oral cavity, and pharynx	73	3.7 (0.46)	1.23	82.2	_	C00-14
Oesophagus	16	1.0 (0.25)	1.17	56.2	_	C15
Stomach	49	2.8 (0.42)	0.85	59.2	_	C16
Colorectum and anus	133	7.6 (0.69) >	1.68	74.4	_	C18-21
Liver	122	6.1 (0.59) <	0.37	15.6	_	C22
Pancreas	34	2.2 (0.39)	1.12	14.7	_	C25
Larynx	39	2.4 (0.39) >	1.75	87.2	_	C32
Lung (including trachea)	35	2.1 (0.38)	1.23	60.0	_	C33-34
Melanoma of skin	8	0.5 (0.19)	0.80	87.5	_	C43
Kaposi sarcoma	11	0.4 (0.13) <	0.46	81.8	_	C46
Prostate	438	27.7 (1.35)	1.10	79.2	_	C61
Testis	5	0.2 (0.07)	0.56	40.0	_	C62
Kidney etc.	15	0.7 (0.19)	0.94	73.3	_	C64-66
Bladder	31	1.8 (0.33)	0.87	83.9	_	C67
Brain and central nervous system	39	1.7 (0.28) >	4.10	82.1	_	C70-72
Thyroid	12	0.6 (0.17)	1.59	75.0	_	C73
Lymphoma	159	7.8 (0.66) >	1.62	54.7	_	C81-88,C90
Leukaemia	48	2.6 (0.39) >	1.87	12.5 <	_	C91–95
Ill-defined (2.6% of total)	41	2.0 (0.33)	1.07	90.2	_	C76-80
All sites except non–melanoma skin	1548	84.9 (2.26) >	1.07	66.5	_	C00-96 exc. C44
		Females				
Site	Cases	ASR (se)	O/E	MV%	DCO%	ICD-10
Lip, oral cavity, and pharynx	44	2.2 (0.35)	1.12	97.7	_	C00-14
Oesophagus	7	0.4 (0.16)	1.02	71.4	_	C15
Stomach	24	1.3 (0.27) <	0.48	62.5	_	C16
Colorectum and anus	112	6.2 (0.62) >	1.63	75.9	_	C18-21
Liver	47	2.4 (0.37) <	0.30	29.8	_	C22
Pancreas	21	1.2 (0.26)	0.92	28.6	_	C25
Larynx	7	0.5 (0.18)	3.26	100.0	_	C32
Lung (including trachea)	23	1.2 (0.27)	1.12	73.9	_	C33-34
Melanoma of skin	14	0.8 (0.23)	1.24	50.0	_	C43
Kaposi sarcoma	7	0.3 (0.11) <	0.46	100.0	_	C46
Breast	747	39.6 (1.52)	1.01	73.8	_	C50
Cervix uteri	455	27.0 (1.32)	0.92	79.8	_	C53
O&U part of uterus	66	4.0 (0.51)	1.21	84.8	_	C54-55
Ovary	96	4.7 (0.51) >	1.30	87.5	_	C56
Kidney etc.	19	0.9 (0.21)	1.26	73.7	_	C64-66
Bladder	13	0.7 (0.21) <	0.58	76.9	_	C67
Brain and central nervous system	35	1.5 (0.26) >	4.47	82.9	_	C70-72
Thyroid	46	2.3 (0.36) >	2.19	78.3	_	C73
Lymphoma	103	4.9 (0.52) >	1.49	54.4	_	C81-88,C90
Leukaemia	34	1.7 (0.31)	1.42	5.9 <	_	C91-95
Ill–defined (2.7% of total)	59	3.1 (0.43)		74.6	_	C76-80
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Significantly lower (<) or higher (>) observed values are marked in bold.

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All sites except non-melanoma skin

ASR (se): the observed age-standardized incidence rates (and their standard errors); O&U: other and unspecified; O/E: the ratio of the observed rates to the estimated rates reported in GLOBOCAN 2012 (Ferlay et al., 2013) for the same region of Africa (eastern, central, southern, or western).

1.02

74.0

115.6 (2.62)

MV%: The percentage of microscopically verified cases; these values are compared against the mean observed values from 14 cancer registries in sub-Saharan Africa: Congo, Brazzaville (2006–2010); The Gambia (2003–2007); Guinea, Conakry (2005–2009); Kenya, Eldoret (2008–2011) and Nairobi (2004–2008); Malawi, Blantyre (2006–2010); Mali, Bamako (2003–2007); Mauritius (2007–2011); Niger, Niamey (2006–2009); Nigeria, Abuja Federal Capital Territory (2009–2012) and Ibadan (2006–2009); South Africa, PROMEC (2003–2007); Uganda, Kyadondo County (2003–2007); and Zimbabwe, Harare: African (2003–2006).

For further definitions and explanations of the terms and abbreviations used in this table, see the corresponding text in this chapter and in Chapter 2: *Processing and presentation of the data* (p. 3).

C00-96 exc. C44

Editorial table 5. Average annual population at risk during the period selected

Registry X (2006-2009)

Population pyramid (average person-years by sex and age group)

