Research

The Royal Society of Medicine

Journal of the Royal Society of Medicine; 2015, Vol. 108(2) 57–67
DOI: 10.1177/0141076814554671

Appraising the quality of sub-Saharan African cancer registration systems that contributed to GLOBOCAN 2008: a review of the literature and critical appraisal

Tim Crocker-Buque and Allyson M Pollock
Centre for Primary Care and Public Health, Queen Mary University of London, Whitechapel, London E12AD, UK
Corresponding author: Tim Crocker-Buque. Email: drtimcb@gmail.com

Abstract

Objective: To critically appraise the quality of sub-Saharan African cancer registration systems that submitted data to GLOBOCAN 2008 with respect to population coverage using publicly available information and to show the use of GLOBOCAN statistics in determining global health priorities.

Design: Sources of cancer registration data for twenty-six sub-Saharan African cancer registries were identified from GLOBOCAN 2008 factsheets. Additional information was extracted from International Agency for Research on Cancer publications. A literature search was conducted to identify studies that reported additional information on data collection methods and provided 27 studies. The websites of the 10 largest funders of development assistance for health were searched for GLOBOCAN citations.

Setting and participants: Twenty-six sub-Saharan African cancer registration systems submitting data to GLOBOCAN 2008 in relation to 21 countries.

Main outcome measures: Information on 15 quality variables were extracted and compared with the international gold standard for cancer registration systems.

Results: Population coverage of the cancer registries ranged from from 2.3% of the population in Kenya to 100% in The Gambia, with a heavy urban bias in all countries. However, 20 countries (300 million people) had no cancer registration systems. Nineteen of the 26 registries failed to meet more than five of the 15 quality criteria and only one country met more than 10. Seven of the 10 largest funders of development assistance for health cite GLOBOCAN statistics in support of policy priorities.

Conclusions: GLOBOCAN 2008 estimates are based on data drawn from poor quality cancer registration systems, with limited or no population registry coverage. It is essential the GLOBOCAN 2012 estimates should provide information on the quality of the data collection and explain the limitations of the estimates. Development organisations and the World Health Organization need to take a more cautious approach when using these data to determine priorities and allocating resources.

Keywords

cancer, epidemiology, sub-Saharan Africa, GLOBOCAN, global health

Background

GLOBOCAN statistics are widely cited and used by national governments and international non-governmental organisations to set global health priorities. GLOBOCAN is a project of the International Agency for Research on Cancer (IARC), the World Health Organization (WHO) body that undertakes research on carcinogens and cancer epidemiology. It uses data reported from local, regional and national cancer registries around the world to estimate incidence, prevalence, mortality and disability adjusted life years lost to cancer. GLOBOCAN published national estimates of cancer epidemiology in 184 countries for 2002 and 2008[1] and has recently released estimates for 2012.[2]

In 2008, GLOBOCAN estimated that of the 36 million worldwide deaths due to non-communicable diseases (NCDs), 7.6 million were from cancer, of which 63% occur in less developed regions; and that around half of the 12.7 million annual incident cancer cases occur in the developing world.[1] Of these, there were 715,000 incident cancer cases and 542,000 deaths in Africa, with increasing incidence of breast and prostate cancer.[3] The accuracy and veracity of GLOBOCAN data in sub-Saharan Africa are of increasing importance as cancer is being promoted as a priority for development funding for health, particularly through the use of human papillomavirus (HPV) vaccination for the prevention of cervical cancer.[4]

Although academics and researchers have cited the GLOBOCAN 2002 estimates more than 14,500 times[5] and GLOBOCAN 2008 estimates almost 6,000 times,[1] no external appraisal has been undertaken of the quality of the data collection methods used by sub-Saharan African registries. Our aim is to describe and critically appraise the publicly available information on population coverage and quality of the cancer registration systems of sub-Saharan African cancer registries that submitted data to GLOBOCAN 2008 against standards recommended for cancer registration systems and to show how GLOBOCAN statistics were used when determining global health priorities between 2010 and 2013.

Methods and analysis

Cancer registries and population coverage

GLOBOCAN 2008 Cancer Factsheets for 41 mainland sub-Saharan African countries (Appendix 3 in the online Supplementary file) were used to identify the 26 contributing registries; registry coverage was compared with country data from the UN World Population 2009 Country Estimates.[6]

Cancer registry methodology

We looked for all publicly available information relating to methods of data collection for each of the 26 registries. The primary source of cancer registration information was IARC publication Cancer in Africa,[7] which provided information on data collection methods and cancer epidemiology statistics for all 26 cancer registries and was the only information source for 10 registries. More detailed information for four registries (Bamako, Mali; The Gambia; Kyadondo, Uganda; and Harare, Zimbabwe) was extracted from Cancer in Five Continents VIII[8] and IX.[9]

GLOBOCAN Data Sources and Methods factsheets contained 22 citations of which only two papers relating to two registries could be sourced in the literature. We were unable to access seven papers relating to six registries and 13 citations related to unpublished material. Although the focus of this study is on the publicly available information, we requested from the IARC the unpublished papers that it had cited, but received no response.

In addition, we undertook a literature search of PubMed and Medline using the terms (cancer AND register OR registry OR registration AND [relevant country]) to identify all studies that reported data collection methods or quality from any of the cancer registries published before April 2013. Of the 27 papers identified through the literature review, 23 studies related to 11 individual registries and four papers covered the sub-Saharan African region. Appendix 2 lists each cancer registry with its respective included papers.

We used the framework previously applied to the cancer registries in Norway[10] and The Gambia[11] adapted from the criteria published by Parkin and Bray of the Descriptive Epidemiology Unit at the IARC.[12,13] Using the UK National Cancer Registry (UKNCR) as a country benchmark, we looked at four domains of registration quality:

(I) Comparability: a measure of how well data classification and coding conforms to international guidelines and best practice.
(II) Validity: whether the reported cases of cancer are accurately recorded in the registry.
(III) Timeliness: relating to both time from diagnosis to registration and from registration to reporting information publicly.
(IV) Completeness: defined as the extent to which the total numbers of cancers are registered on a database. Childhood cancer rates are used as an indicator to assess registry completeness. Deviation from an expected range suggests incomplete registration of childhood cancer and can be used to infer risk of incompleteness generally. The expected values of incidence rates per 100,000 for the upper and lower deciles of childhood cancer by age group were extracted from Cancer in 5 Continents VIII and compared to the childhood cancer rates from Cancer in Africa (2003) and UK data from 2009.[14]

Use of GLOBOCAN data in priority setting

The top ten largest global funders of development assistance for health were identified from the Institute of Health Metrics and Evaluation report 'Financing Global Health'.[15] Their websites were then searched using the terms 'GLOBOCAN', 'IARC' and 'cancer' to identify if GLOBOCAN statistics were used and to look at how GLOBOCAN statistics from sub-Saharan Africa were cited.

Limitations

The IARC has access to additional information that is not available in the public domain and therefore is better placed to evaluate cancer registry quality. However, it has not published any analysis of the collection methodology used by registries that contributed to GLOBOCAN 2008. No new information had been published by the IARC on cancer registry quality since Cancer in 5 Continents IX in 2007. This study therefore provides a record of the information available in the public domain for use by funders when using GLOBOCAN statistics to determine priorities.

Results

Cancer registries and population coverage

In the 41 mainland countries in sub-Saharan Africa (Appendix 3 in the online Supplementary file), 26 registries reported data on a total of 21 countries to GLOBOCAN 2008 (Appendix 1 in the online Supplementary file). Of these, 20 registries are population based: four have national coverage (Botswana, The Gambia, Namibia and Swaziland); 16 cover a region, district or city. Five are pathology based and one registry collects data from a single hospital.

Registry coverage ranges from approximately 2.3% of the population in Kenya to 37.3% and 100% in Congo and The Gambia, respectively, with a bias towards urban areas and very limited rural coverage. By comparison, the UKNCR provides complete coverage of the UK population through a network of 11 regional registries. For the 20 countries with no cancer registration system, GLOBOCAN used an average of neighbouring countries.

Cancer registration methodology

Number of registries meeting recommended registration criteria (Table 1). Of the 26 registries, 19 met less than five of the 15 criteria and only The Gambia met more than 10. A full table reporting the results for each cancer registry of the four domains and 15 variables is presented in Appendix 1 in the online Supplementary file.

Number of registries meetings the criteria for each of the 15 variables within the four domains. Table 2 displays the number and proportion of the 26 sub-Saharan African cancer registries that meet each of the four domains and 15 variables of cancer registration methodological standards as adapted from Parkin and Bray (2009) with the UKNCR comparator.

(I) *Comparability*

Of the 26 registries, 16 provided no data on coding. For the 10 registries reporting ICD code, five used ICD-O3, three used ICD-10 and two used both. The UKNCR uses the Po/99/03 Definition of Diagnosis Date.[40] The Gambian Cancer Registry uses the IARC Guidelines on Cancer Registration,[41] but this information is not available for any other registries.

None of the registries have published information on how they determine date when registering an incident cancer in a registry and only three on rules for coding multiple primaries to ensure consistency in registration practices.

No information was available on incidental diagnoses (the proportion of cancers that are detected in asymptomatic people) as few sub-Saharan African countries have comprehensive population screening programmes. For example, Zimbabwe has a national screening programme for breast and cervical cancer; however, there is no information available on the proportion of registrations that result from screening. Screening contributes some cancer diagnoses to the Kampala registry in Uganda. However, it is not a national programme and is only available for patients who pay privately.

(II) *Validity*

Although 81% of the registries published the proportion of cancers in each registry that have been verified through histological examination by a pathologist, exfoliative cytology or peripheral blood examination (morphological verification rate, MV%), these rates were highly variable (Appendix 1 in the online Supplementary file). In population-based registries, MV% ranged from 15% for male patients in The Gambia National Registry to 96% in female patients in the Namibian Cancer Registry. This reflects the resources available in countries to perform histological diagnostics and also the methods by which cancers are registered.

Information on the proportion of cancers that are registered only from information on a death certificate (death certification only rate, DCO%) was only available for The Gambian National Cancer Registry and the Harare Cancer Registry. No information on death certification is available for 15 registries. Of the nine others, 4 do not routinely certify death; Nigeria only has limited death certification; the Abidjan registry was unable to access death certificates from local authorities; autopsies are not performed in Guinea unless someone dies in hospital and so there are a limited source of registrations; Mali has mandatory death certification, but no DCO% is published; and death certificates in Niger do not state cause of death.

Information on reabstracting/recoding audits is only available for the Gambian National Cancer Registry, where the registrar undertakes audits every quarter. These audits are undertaken to evaluate registry agreement with source documentation and agreement among data collectors and have shown 94% agreement between the audit result and the original cancer registrations. Six other registries report using 'validity checks' but no further information is available on the results. The UKNCR has also not published information on the use or results of reabstracting/recoding audits.

Seven registries report information on demographic completeness and below is a list of registries that have reported incompleteness (<80%) in certain areas:

- UKNCR – ethnicity of patients
- Kampala – date of birth, patient ID, cancer stage and treatment

Table 1. The extent to which each of the 26 sub-Saharan African cancer registries meets the 15 quality criteria, as adapted from Parkin and Bray (2009). (See Table 2 for definitions of variables A-E by domain.)

	Quality variables				
Country (name of registry)	Comparability A, B, C, D, E	Validity A, B, C, D, E	Timeliness A, B	Completeness A, B, C	Total
UK (National Cancer Registry)[14]	*5*	*4*	*2*	*3*	*14*
Botswana*	0	0	1	0	1
Burkina Faso (Ouagadougou)*	0	2	1	0	3
Cameroon (Yaounde)*	0	1	1	0	2
Congo (Brazzaville)*	0	1	1	0	2
Cote d'Ivoire (Abidjan)*[16]	1	3	1	1	6
Gabon (Gabon)*[17]	0	1	1	0	2
Guinea (Conakry)*[18]	1	2	1	0	4
Kenya (Eldoret)*[19]	1	2	1	0	4
Kenya (Nairobi)*	0	1	1	0	2
Malawi (Blantyre)*[20,21]	1	2	1	1	5
Mali (Bamako)*†‡	0	3	1	1	5
Namibia*	0	2	1	1	4
Niger (Niamey)*	0	2	1	1	4
Nigeria (Ibadan)*[22,23]	1	3	1	1	6
Nigeria (Ilorin)*[22,23]	1	1	1	0	3
Rwanda (Butare)*[24]	1	2	1	0	4
South Africa (South Africa)*[25,26]	0	2	1	1	4
Swaziland*	0	2	1	1	4
Tanzania (Kilimanjaro)*	0	1	1	0	2
Tanzania (Dar Es Salam)*	0	1	1	0	2
The Gambia*†‡[27–30]	4	5	1	1	11
Uganda (Kampala)*†‡[31–35]	2	4	2	1	9
Uganda (Mbarara)*[36]	0	1	1	0	2
Zambia*	0	1	1	0	2
Zimbabwe (Harare, black population)*†‡[37–39]	2	3	1	1	7
Zimbabwe (Bulawayo district)*	0	0	1	0	1

*IARC, Cancer in Africa (2003).
†IARC, Cancer in 5 Continents IX (2007).
‡IARC, Cancer in 5 Continents VIII (2002).
All other sources listed in Appendix 2.

Table 2. The number and proportion of the 26 sub-Saharan African cancer registries meeting each of the 15 cancer registration quality variables, as adapted from Bray and Parkin (2009).

Domain	Variable	Definition	Number of registries meeting the criteria, $n = 26$ (%)*	Criteria met by the UKNCR (Yes/No)[†]
(I) Comparability	A. Coding	Named ICD diagnostic codes	10 (36)	Y
	B. Definition of diagnosis date	Named international guidelines used	1 (4)	Y
	C. Incidence date	Named incidence date criteria used	0 (0)	Y
	D. Coding multiple primaries	Named international guidelines used	3 (12)	Y
	E. Incidental diagnoses	Proportion of cases found through screening programmes is available	0 (0)	Y
(II) Validity	A. Morphological verification rate (MV%)	MV% available for cases in register	21 (81)	Y
	B. Death certification only rate (DCO%)	DCO% available for cases in register	2 (8)	Y
	C. Reabstracting and recoding audit	Audit undertaken	1 (4)	N
	D. Demographic completeness	Information available on demographic criteria that are <80% complete	7 (27)	Y
	E. Database consistency	Named programme used to maintain database consistency	13 (50)	Y
(III) Timeliness	A. Publication of dataset	Date of most recent dataset published	26 (100)	Y
	B. Time taken from cancer diagnosis to registration	Diagnosis to registration time published	1 (4)	Y
(IV) Completeness	A. Mortality incidence ratio	M:I published for cases in register	0 (0)	Y
	B. Notifications per case	Average number of notifications received by the registrar for each case	0 (0)	Y
	C. Childhood cancer incidence	Incidence of childhood cancer published	12 (46)	Y

*Sources listed in Appendix 2.

[†] ONS, 2012.

- Zambia – described as very incomplete
- Abidjan – reported age unreliable for many older people
- GNCR – 18.6% patients have age missing
- Namibia – residency information
- South Africa – ethnicity of patients (since 1993)
- Swaziland – geographic information

To maintain electronic database consistency 12 registries report using CanReg 4 system, which is a software program produced by the IARC specifically for cancer registration (http://www.iacr.com.fr/canreg4.htm). Rwanda's Butare Registry used the online EGRET system, a much older software program, but has not reported since 1993. This information is not available for any of the other registries.

(III) *Timeliness*

No internationally agreed standard for timeliness exists. Fourteen of the registries submitted data which had been collected more than five years previously while four registries submitted data that were more than 10 years old, for example the Rwanda data originated in 1991.

Registries should also look at the time taken between a cancer being diagnosed and its entry on a register. The UKNCR has a target that 'all cases diagnosed in a given calendar year should have been completed, entered onto the registry computer system and sent to ONS within 18 months of the end of the calendar year.'[42] For 2009, this was achieved for 101.7% of expected cases on average compared to the 2005–2007 datasets. The Kampala registry in Uganda uses a similar standard and achieved a 90% expected rate from 1994 to 1996. This information was not available for any other registries.

(IV) *Completeness*

Mortality:incidence ratios are not available for any of the registries due to lack of data. M:I ratios compare the number of cancer deaths recorded by a mechanism external to the registry (e.g. vital statistics registration) compared to the number of incident cancer diagnoses recorded and rely on the comparison of cancer registry data with a parallel death registration system. Greater M:I ratio suggests registry incompleteness. The M:I ratio for the UKNCR is 0.51 for male cases (compared to 0.54 expected) and 0.48 for female cases (compared to 0.50 expected).

No cancer registries publish the number of notifications received for each case registered.

The incidence estimates of childhood cancer are below expected limits (Table 3), suggesting under-registration, with the exception of cancers in white South African children aged 0–4 years and children aged 5–9 years registered in Kampala. The numbers of cases from which estimates are calculated are small, ranging from 93 to 2295 registered over a period of 2 to 10 years. The timeliness of the data is also poorer than is the case with adults. More recent information is available from The Gambian National Cancer Registry, where incidence rates in children between 1990 to 1994 range from 1.9/100,000 in girls aged 0–4 years and 5.8/100,000 in boys aged 10–14 years. These are lower than the estimates from Cancer in Africa (2003) and far below the expected reference range. The authors also note that rates were two to threefold higher in urban compared to rural children.

Use of GLOBOCAN data in priority setting

The top 10 funders of development assistance for health are listed in Table 4 alongside examples of how GLOBOCAN estimates are used in priority setting. The only U.S. Agency for International Development and the Global Fund do not fund cancer projects.[43,44] Although the UK Department for International Development lists NCDs as part of its policy priorities but provides no data to support the priorities, and no NCD or cancer projects were listed in the 2011–2012 annual report.[45] The remaining seven cite GLOBOCAN 2008 statistics in support of tackling NCDs and cervical cancer with HPV vaccine as a priority area.

Discussion

GLOBOCAN 2008 estimates of cancer prevalence, incidence and mortality for sub-Saharan African countries were based on incomplete population and country coverage. Most countries have weak cancer registration systems, with the notable exception of the Gambian National Cancer Registry.[11] Twenty sub-Saharan African countries covering a population of almost 300 million people had no cancer registration systems. In countries with registries cases are predominantly derived from large hospitals in urban centres. This may result in disproportionate registration of cancers of those able or willing to seek medical attention or may be distorted by other health seeking behavior by rural populations.[60] In most cases, the weaknesses in the data collection mean that the epidemiological statistics estimated are not generaliseable to national populations or to other sub-Saharan African countries.

Table 3. Incidence and numbers of childhood cancer by age group reported from 13 sub-Saharan African cancer registries.

Registry	Year of data collection	Number of cases	Incidence (ASR per 100,000) by age group (years)		
			0–4	5–9	10–14
Expected childhood cancer incidence range (limits of upper and lower deciles)[*]			*9.7–24.7*	*6.9–15.6*	*6.8–15.0*
Cote d'Ivoire (Abidjan)[†]	1995–1997	137	3.76^ (not disaggregated by age)		
Guinea (Conakry)[†]	1993–1999	193	4.45^	5.32^	10.21
Malawi (Blantyre)[†]	1991–2001	263	5.87^	9.04	7.33
Mali (Bamako)[*†‡]	1988–1997	133	3.80^	4.50^	3.50^
Namibia[†]	1995–1998	83	3.05^	1.68^	4.77^
Niger (Niamey)[†]	1993–1999	119	3.98^	7.07	11.52
Nigeria (Ibadan)[†]	1993–1999	176	14.41	8.71	10.07
South Africa (black)[†]	1989–1992	2295	5.40^	5.29^	5.34^
South Africa (white)[†]	1989–1992	819	26.74[a]	14.76	14.11
Swaziland[†]	1989–1999	93	7.51^	5.57^	3.82^
The Gambia[*†‡]	1988–1998	162	3.19^	3.18^	4.15^
Uganda (Kampala)[*†‡]	1993–1997	415	16.60	20.35[a]	15.15
Zimbabwe (Harare, black population)[*†‡]	1990–1997	386	11.44	10.21	11.11

Lower than expected incidence (that may suggest under-registration) is marked with ^ and higher than expected incidence (that may suggest over-registration) is marked with a.

[*] IARC, Cancer in 5 Continents VIII (2002).

[†] IARC, Cancer in Africa (2003).

[‡] IARC, Cancer in 5 Continents IX (2007).

GLOBOCAN publishes cancer epidemiology estimates for 184 countries; however, estimates for countries with universal cancer registration coverage and high quality data collection systems are given equal weight to those countries with poor quality data and limited coverage. This has led to GLOBOCAN statistics being widely cited without qualification of their reliability and used to determine funding priorities from a wide range of international global health funding organisations.

One notable example of this is cervical cancer, where GLOBOCAN statistics have been used to support rollout of HPV vaccine[4,55] and are often the only epidemiological data cited. The absence of strong surveillance systems for monitoring incidence and changes in mortality cast serious doubt on the ability of the international community to evaluate the effectiveness and safety of the programme.

This study demonstrates the information that was available in the public domain for analysis by individuals and organisations when using the GLOBOCAN 2008 estimates. It also demonstrates the influence these estimates have had on a wide range of international funders. However, this study is necessarily limited to the information in the public domain and is therefore not a complete analysis of all the information relating to cancer registry data quality, which is held by the IARC. Aside from the information described in this study, any additional data are held by the IARC and not available for public scrutiny.

Since the publication of the 2008 GLOBOCAN estimates in 2010, the African Cancer Registry Network (http://afcrn.org/) has been founded in order to improve data quality and population coverage. This paper provides an important baseline against which to judge GLOBOCAN estimates for 2012, which have recently been published.

In the new 2012 factsheets, the IARC has now included an 'indice of quality' under the 'data, sources

Table 4. GLOBOCAN 2008 statistics cited on the websites of the 10 biggest funders of development assistance for health as identified in the Institute for Health Metrics and Evaluation 2012 report.

Organisation/channel	Development assistance for health (2010, US$m)*	Publication	Example statistic	Source
United States Government (USAID)[46]	7,119.53	–	–	–
Global fund to fight AIDS, tuberculosis and Malaria[44]	3,292.85	–	–	–
World Health Organization (WHO)[47]	2120.35	Action plan for the control of NCDs 2013–2020[48]	63% of 57 million deaths that occurred globally in 2008 were due to non-communicable diseases, [of which] cancers [caused] 21%	GLOBOCAN 2008
World Bank[49] • International Bank for Reconstruction and Development • International Development Association	1225.43 822.33	The growing Danger of Non Communicable Diseases[50]	By 2030, cancer incidence is projected to increase by 70% in middle-income countries and 82% in lower income countries	GLOBOCAN 2008
		The challenge of non-communicable diseases and road traffic injuries in sub-Saharan Africa[51]	The burden from cancer is expected to more than double between 2008 and 2030, with new cases rising from 681,000 to 1.6 million and deaths rising from 512,000 to 1.2 million over that period. The regions in the world with the highest risk for cervical cancer are Western and Eastern Africa	GLOBOCAN 2008
United Kingdom Government (DfID)[45]	1168.61	–	–	–
Bill & Melinda Gates Foundation[52]	1123.28	Press Release: Alliance for cervical cancer prevention receives $50 million gift from Bill and Melinda Gates[53]	Cervical cancer kills more than 200,000 women annually worldwide	GLOBOCAN 2008
GAVI Alliance[54]	1068.00	HPV factsheet[55]	Approximately 275,000 women die every year from cervical cancer. Over 85% of those deaths occur in developing countries	GLOBOCAN 2008

(continued)

Table 4. Continued.

Organisation/channel	Development assistance for health (2010, US$m)*	Publication	Example statistic	Source
United Nations Children's Fund (UNICEF)[56]	847.32	Request for proposal – pneumococcal, rotavirus and human papillomavirus. Vaccines for middle income countries[57]	Cervical cancer remains the third most common cancer in women worldwide	GLOBOCAN 2008
United Nations Population Fund (UNFPA)[58]	823.80	Comprehensive cervical cancer prevention and control – a guide for countries[59]	[Cervical cancer is a] public health problem worldwide as it claims the lives of more than 270,000 women every year [and] the majority of cervical cancer deaths (85%) occur in women living in low- and middle-income countries	GLOBOCAN 2008

*Extracted from: *Financing Global Health 2012: The End of the Golden Age?* Seattle, WA: Institute of Health Metrics and Evaluation, 2012.

and methods' sections, consisting of an alphabetic ranking for the availability of incidence data (A to G) and numeric ranking for the availability of mortality data (1 to 6).[61] For example, Rwanda is ranked F6 meaning frequency data are used for incidence estimates and no mortality data are available.[62] This is a welcome improvement; however, it is not prominently displayed and may lead to further use of GLOBOCAN estimates without consideration of their quality.

The IARC have since removed the GLOBOCAN 2008 factsheets from their website and declined to provide us with copies for reference when requested by email. This paper therefore provides an important record of their contents, particularly as these estimates had a substantial influence on funding priorities between 2010 and 2014. This paper will enable a comparison of the GLOBOCAN between the 2008 and 2012 estimates for sub-Saharan Africa.

The WHO has a key role in setting priorities for improving global health, as do the major development funders. Using GLOBOCAN estimates without proper consideration of their quality will result in misallocation of resources. The true incidence and prevalence of cancer in sub-Saharan Africa remains largely unknown. Much greater emphasis needs to be placed on improving the quality of data collected by these registries, especially where funders use them in support of major global health interventions.

Conclusions

This study presents the first critical appraisal of the publicly available information on the quality of cancer registration methodology in sub-Saharan African cancer registries used by GLOBOCAN 2008 to estimate cancer epidemiology. GLOBOCAN 2008 estimates were based on data from weak cancer registration systems and very limited population coverage. GLOBOCAN 2008 estimates on cancer incidence and mortality have been used to justify significant policy and funding decisions without sufficient scrutiny. GLOBOCAN has begin to publish more information on the quality of the registries from which their statistics are estimated; however, this should be displayed more prominently with further information provided on the caveats and limitations in their application. Development organisations and the WHO need to take a more cautious approach when using these estimates to determine priorities and when allocating resources.

Declarations

Competing interests: None declared

Funding: None declared

Ethical approval: Ethics Committee approval was not required because the analysis used only non-sensitive non-identifiable secondary data available in the public domain.

Guarantor: AMP

Contributorship: TC-B undertook the research and wrote the paper. AMP assisted with the research and edited the paper.

Acknowledgements: Louisa Harding-Edgar, Petra Sevcikova and Laura Heggie for starting this work and their support throughout.

Provenance: Not commissioned; peer-reviewed by Raghib Ali

References

1. Ferlay J, Shin H-R, Bray F, Forman D, Mathers C and Parkin DM. Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *Int J Cancer* 2010; 127: 2893–2917.
2. IARC. *GLOBOCAN*, 2013. See http://globocan.iarc.fr/Default.aspx (last checked 20 December 2013).
3. Jemal A, Bray F, Forman D, O'Brien M, Ferlay J, Center M, et al. Cancer burden in Africa and opportunities for prevention. *Cancer* 2012; 118: 4372–4384.
4. WHO. *Human Papillomavirus (HPV)*. Geneva, Switzerland: World Health Organization, 2013. See http://www.who.int/immunization/topics/hpv/en/ (last checked 20 December 2013).
5. Parkin DM, Bray F, Ferlay J and Pisani P. Global cancer statistics, 2002. *CA Cancer J Clin* 2005; 55: 74–108.
6. United Nations. *World Population Prospects: The 2008 Revision Highlights*. New York: United Nations, 2008.
7. Sitas F and Whelan SL. *Cancer in Africa*. Lyon, France: IARC, 2003.
8. IARC. *Cancer Incidence in Five Continents, Vol. VIII* (Parkin D, Whelan S, Ferlay J, Teppo L, Thomas D, Eds). Lyon, France: IARC, 2002.
9. IARC. *Cancer Incidence in 5 Continents IX*. Lyon, France: IARC, 2007.
10. Larsen IK, Småstuen M, Johannesen TB, Langmark F, Parkin DM, Bray F, et al. Data quality at the Cancer Registry of Norway: an overview of comparability, completeness, validity and timeliness. *Eur J Cancer* 2009; 45: 1218–1231.
11. Shimakawa Y, Bah E, Wild CP and Hall AJ. Evaluation of data quality at the Gambia national cancer registry. *Int J Cancer* 2013; 132: 658–665.
12. Bray F and Parkin DM. Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. *Eur J Cancer* 2009; 45: 747–755.
13. Parkin DM and Bray F. Evaluation of data quality in the cancer registry: principles and methods. Part II: completeness. *Eur J Cancer* 2009; 45: 756–764.
14. Office for National Statistics (ONS). *Cancer Statistics Registrations: Registrations of Cancer Diagnosed in 2009, England*. London: ONS, 2009, pp.1–39.
15. IHME. *Financing Global Health 2012: The End of the Golden Age?* Seattle, WA: Institute of Health Metrics and Evaluation, 2012.
16. Echimane AK, Ahnoux AA, Adoubi I, Hien S, M'Bra K, D'Horpock A, et al. Cancer incidence in Abidjan, Ivory Coast – first results from the cancer registry, 1995–1997. *Cancer* 2000; 89: 653–663.
17. Nze-Nguema F, Sankaranarayanan R, Barthelemy M, Nguizi-Ogoula S, Whelan S and Minko-Mi-Etoua D. Cancer in Gabon, 1984–1993: a pathology registry based relative frequency study. *Bull Cancer* 1996; 83: 693–696.
18. Koulibaly M, Kabba IS, Cissé A, Diallo SB, Diallo MB, Keita N, et al. Cancer incidence in Conakry, Guinea: first results from the Cancer Registry 1992–1995. *Int J Cancer* 1997; 70: 39–45.
19. Tenge CN, Kuremu RT, Buziba NG, Patel K and Were P. Burden and pattern of cancer in Western Kenya. *East Afr Med J* 2009; 86: 7–10.
20. Banda LT, Parkin DM, Dzamalala CP and Liomba NG. Cancer incidence in Blantyre, Malawi 1994–1998. *Trop Med Int Health* 2001; 6: 296–304.
21. Msyamboza KP, Dzamalala C, Mdokwe C, Kamiza S, Lemerani M, Dzowela T, et al. Burden of cancer in Malawi; common types, incidence and trends: national population-based cancer registry. *BMC Res Notes* 2012; 5: 149.
22. Jedy-Agba E, Curado MP, Ogunbiyi O, Oga E, Fabowale T, Igbinoba F, et al. Cancer incidence in Nigeria: a report from population-based cancer registries. *Cancer Epidemiol* 2012; 36: e271–e278.
23. Jedy-Agba EE, Curado M-P, Oga E, Samaila MO, Ezeome ER, Obiorah C, et al. The role of hospital-based cancer registries in low and middle income countries – the Nigerian Case Study. *Cancer Epidemiol* 2012; 36: 430–435.
24. Newton R, Ngilimana PJ, Grulich A, Beral V, Sindikubwabo B, Nganyira A, et al. Cancer in Rwanda. *Int J Cancer* 1996; 66: 75–81.
25. Somdyala NI, Bradshaw D, Gelderblom WC and Parkin DM. Cancer incidence in a rural population of South Africa, 1998–2002. *Int J Cancer* 2010; 127: 2420–2429.
26. Advisory Committee, National Cancer Registry. Usefulness of cancer registries in epidemiological research and cancer control. *SAMJ* 1995; 85: 748–750.
27. Shimakawa Y, Bah E, Wild CP and Hall AJ. Evaluation of data quality at the Gambia national cancer registry. *Int J Cancer* 2013; 132: 658–665.
28. Bah E, Sam O, Whittle H, Ramanakumar A and Sankaranarayanan R. Cancer survival in the Gambia, 1993–1997. *IARC Sci Publ* 2011; 162: 97–100.
29. Sighoko D, Bah E, Haukka J, McCormack VA, Aka EP, Bourgeois D, et al. Population-based breast (female) and cervix cancer rates in the Gambia: evidence of ethnicity-related variations. *Int J Cancer* 2010; 127: 2248–2256.
30. Bah E, Parkin DM, Hall AJ, Jack AD and Whittle H. Cancer in the Gambia: 1988–97. *Br J Cancer* 2001; 84: 1207–1214.
31. Wabinga H, Parkin DM, Nambooze S and Amero J. Cancer survival in Kampala, Uganda, 1993–1997. *IARC Sci Publ* 2011; 162: 243–247.
32. Parkin DM, Nambooze S, Wabwire-Mangen F and Wabinga HR. Changing cancer incidence in Kampala, Uganda, 1991–2006. *Int J Cancer* 2010; 126: 1187–1195.

33. Gondos A, Brenner H, Wabinga H and Parkin DM. Cancer survival in Kampala, Uganda. *Br J Cancer* 2005; 92: 1808–1812.
34. Parkin DM, Wabinga H and Nambooze S. Completeness in an African cancer registry. *Cancer Causes Control* 2001; 12: 147–152.
35. Wabinga HR, Parkin DM, Wabwire-Mangen F and Nambooze S. Trends in cancer incidence in Kyadondo County, Uganda, 1960–1997. *Br J Cancer* 2000; 82: 1585–1592.
36. Wabinga H. Pattern of cancer in Mbarara, Uganda. *East Afr Med J* 2002; 79: 193–197.
37. Chokunonga E, Borok M, Chirenje Z, Nyakabau A and Parkin D. Trends in the incidence of cancer in the black population of Harare, Zimbabwe 1991–2010. *Int J Cancer* 2013; 133: 721–729.
38. Chokunonga E, Borok MZ, Chirenje ZM, Nyabakau AM and Parkin DM. Cancer survival in Harare, Zimbabwe, 1993–1997. *IARC Sci Publ* 2011; 162: 249–255.
39. Chokunonga E, Levy LM, Bassett MT, Mauchaza BG, Thomas DB and Parkin DM. Cancer incidence in the African population of Harare, Zimbabwe: second results from the cancer registry 1993–1995. *Int J Cancer* 2000; 85: 54–59.
40. UKACR. Po/99/03 *Definition of Diagnosis Date*. 2013. See http://www.ukacr.org/content/po9903-definition-diagnosis-date-0 (last checked 28 January 2013).
41. Jensen OM, Parkin DM, MacLennan R, Muir CS and Skeet R. Cancer registration: principles and methods. *IARC Sci Publ* 1991; 95: 1–288.
42. UK Association of Cancer Registries. *UKACR Quality and Performance Indicators*, 2010. See: http://www.ukacr.org/sites/default/files/UKACR%20report2011_final_0.pdf. (Last checked 26th September 2014).
43. USAID. *USAID Policy Framework 2011–2015*, 2011. See: http://www.usaid.gov/sites/default/files/documents/1870/USAID%20Policy%20Framework%202011-2015.PDF (last checked 24th September 2014).
44. The Global Fund. *The Global Fund to Fight AIDS, Tuberculosis and Malaria*, 2013. See http://www.theglobalfund.org/en/ (last checked 20 December 2013).
45. DfID. *Annual Report and Accounts and Accounts*, 2013. London: Department for International Development. See: https://www.gov.uk/government/publications/dfid-annual-report-and-accounts-2012-13 (last accessed 24 September 2014).
46. USAID. 2013. See http://www.usaid.gov/ (last checked 20 December 2013).
47. WHO. 2013. See http://www.who.int/en/ (last checked 12 December 2013).
48. WHO. *2008–2013 Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases*. Geneva, Switzerland: World Health Organization, 2008.
49. World Bank. *World Bank Group, 2013*. See http://www.worldbank.org/ (last checked 12 December 2013).
50. The World Bank. *The Growing Danger of Non Communicable Diseases: Acting Now to Reverse Course* 2011. See: http://siteresources.worldbank.org/HEALTHNUTRITIONANDPOPULATION/Resources/Peer-Reviewed-Publications/WBDeepeningCrisis.pdf (last accessed 24th September 2014).
51. Marquez PV and Farrington JL. *The Challenge of Non-Communicable Diseases and Road Traffic Injuries in Sub-Saharan Africa. An Overview*. Washington, DC: World Bank, 2013.
52. Bill & Melinda Gates Foundation. www.gatesfoundation.org, 2013. See: http://www.gatesfoundation.org/ (last checked 20 December 2013).
53. Bill & Melinda Gates Foundation. *Alliance for Cervical Cancer Prevention Receives $50 Million Gift From Bill and Melinda Gates*, 2013. See http://www.gatesfoundation.org/Media-Center/Press-Releases/1999/09/Alliance-for-Cervical-Cancer-Prevention (last checked 12 December 2013).
54. GAVI. *GAVI Alliance*, 2013. See http://www.gavialliance.org/ (last checked 20 January 2013).
55. GAVI Alliance. *HPV (human papillomavirus) Factsheet*, 2013. See: http://www.gavi.org/Library/Publications/GAVI-fact-sheets/Factsheet-HPV-(human-papillomavirus)/ (last accessed 24th September 2014).
56. UNICEF. www.unicef.org, 2013. See http://www.unicef.org/ (last checked 12 December 2013).
57. UNICEF. *Request for Proposal: Pneumococcal, Rotavirus and Human Papillomavirus Vaccines*, 2012. See: http://www.unicef.org/videoaudio/PDFs/RFP-DAN-2012-501580.pdf (last checked 24th September 2014).
58. UNFPA. www.unfpa.org, 2013. See http://www.unfpa.org/public/ (last checked 12 December 2013).
59. UNFPA. *Comprehensive Cervical Cancer Prevention and Control: Programme Guidance for Countiries*, 2011. See: https://www.unfpa.org/webdav/site/global/shared/ENGLISH-%20Cervical%20Cancer%20Guidance.pdf (last checked 24th September 2014).
60. Sitas F, Parkin M, Chirenje Z, Stein L, Mqoqi N and Wabinga H. *Chapter 20: Cancers. Disease and Mortality in Sub-Saharan Africa*, 2nd ed. Washington, DC: World Bank, 2006.
61. IARC. *Data Sources and Methods, GLOBOCAN 2012*, 2013. See http://globocan.iarc.fr/Pages/DataSource_and_methods.aspx (last checked 17 June 2014).
62. IARC. *Rwanda Factsheet. GLOBOCAN 2012*, 2013. See http://globocan.iarc.fr/Pages/fact_sheets_population.aspx (last checked 17 June 2014).
63. Bah E, Hall AJ and Inskip HM. The first 2 years of the Gambian National Cancer Registry. *Br J Cancer* 1990; 62: 647–650. (See http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1971498&tool=pmcentrez&rendertype=abstract).