



Cancer Intelligence beyond the UK

David Forman

International Agency for Research on Cancer
Lyon, France

NCIN Cancer Outcomes Conference-2013



The worldwide burden of cancer

- UK 2008 (info.cancerresearchuk.org)
- 310,000 new cases and 156,000 cancer-related deaths
- World 2008 (globocan.iarc.fr)
- 12.7m new cases and 7.6m cancer-related deaths
- 56% of new cancer cases and 63% of deaths in developing regions of the world

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World Health
Organization

The worldwide burden of cancer

- UK 2030
 - c. 400,000 new cases and 210,000 cancer-related deaths
 - Increases of 29% and 26% from 2008
- World 2030
 - c. 21.4m new cases and 13.1m cancer-related deaths
 - Increases of 69% and 72% from 2008

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*assuming no change in risk from 2008

globocan.iarc.fr

Cancer Intelligence beyond the UK

What can we learn from others?

and...

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Cancer Intelligence beyond the UK

What can we learn from others?

and...

what can others learn from us?

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Cancer Intelligence beyond the UK

Section of Cancer Information at IARC:

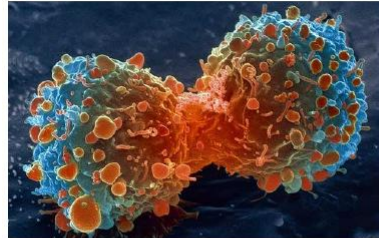
- Collect, analyse and disseminate information on the global burden of cancer
 - Cancer Incidence in Five Continents
 - International Incidence of Childhood Cancer
 - GLOBOCAN
- Support capacity building programmes for cancer registries worldwide, especially in low and middle-income countries
- Conduct research on the descriptive epidemiology of cancer

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Cancer database could save thousands of lives

A "game-changing" new cancer database that could save thousands of lives a year will be announced today.



A new cancer database is expected to be a 'game-changer' in cancer care.

By Rona Silverman
6:00AM BST 12 Jan 2013

Millions of patient records, detailing each cancer and the method of treatment used, will be collated to form the biggest cancer registration service in the world.

The system is expected to lead to each patient benefiting from highly personalised treatments.

It will bring together clinical information on all 350,000 cancers diagnosed in England and will include more than 11 million historical records of cases from as far back as 30 years ago, The Times reported.

Cancer specialists across the country will then, for the first time, be able to draw on the extensive bank of detailed clinical data when working out how to treat each new case.

Jem Rashbass, who leads the Cancer Registration Service at Public Health England, hailed it as "the most comprehensive, detailed and rich clinical dataset on cancer patients anywhere in the world."

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"the most comprehensive, detailed and rich clinical dataset on cancer patients anywhere in the world."

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“the most comprehensive, detailed and rich clinical dataset on cancer patients anywhere in the world.”

- Can the UK learn from elsewhere in the world?

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“the most comprehensive, detailed and rich clinical dataset on cancer patients anywhere in the world.”

- Can the UK learn from elsewhere in the world?
- Can the UK share with the rest of the world?

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“the most comprehensive, detailed and rich clinical dataset on cancer patients anywhere in the world.”

- Can the UK learn from elsewhere in the world?
- Can the UK share with the rest of the world?
- What can others learn from the UK?

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Can the UK learn from elsewhere in the world?

- Approximately half (96) the countries in the world have population-based cancer registries and two-thirds of these (62) are national
- Wide variation in cancer registry cultures and resources (3-140 staff)
- Much underlying common practice (reflected in training)
- Level of international support and practice sharing has historically been very high (International Association of Cancer Registries)
- Largely this relates to core registry data items
- But:

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Can the UK learn from elsewhere in the world?

- Many aspects of the new UK cancer information landscape are being collected elsewhere:
 - Each state in Germany has a clinical cancer registry collecting detailed information on stage and treatment (including chemo);
 - Sweden has a national network of site specific clinical cancer registries collecting similar data;
 - The Netherlands is developing systems for automated capture of comorbidities and PROMS;
 - Several Australian states have detailed radiotherapy treatment data;
 - Many countries are linking Hospital Activity data to registry datasets.
- There have never been any systematic attempts to harmonise collection of such data internationally



Comparability of stage data in cancer registries in six countries: lessons from the International Cancer Benchmarking Partnership

Sarah Walters¹, Camille Maringe¹, John Butler², James D. Brierley³, Bernard Rachet¹ and Michel P. Coleman¹

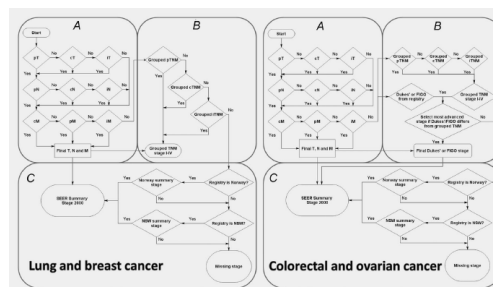
¹Cancer Research UK Cancer Survival Group, Department of Non-Communicable Disease Epidemiology, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom

²St Bartholomew's and Royal Marsden Hospitals, London, United Kingdom

³Department of Radiation Oncology, Princess Margaret Hospital, Toronto, Ontario, Canada

Table 4. Proportions of patients to whom a valid stage at diagnosis could be assigned, by jurisdiction^a

Jurisdiction	Cancer and period of diagnosis							
	Colon/rectum 2000-2007		Lung 2006-2007		Breast 2000-2007		Ovary 2006-2007	
	Ischemic	SEER	SEER	SEER	SEER	SEER	SEER	SEER
New South Wales	90.6	77.2	92.1	98.3				
Victoria	2.6	2.6	0.0	7.4	0.0	0.0		
Alberta	57.3	57.3	95.1	94.0	50.1	50.0	74.5	74.5
British Columbia	41.5	41.5	44.7	44.7	76.5	76.5	69.9	69.9
Manitoba	57.1	57.1	94.2	93.2	85.5	87.5	90.5	90.5
Ontario ^b	81.6	81.6	75.7	59.0	89.1	53.4	68.7	68.7
Denmark ^c	78.8	78.9	89.2	88.7	88.7	77.2	77.2	77.2
Norway	90.4	90.4	90.5	87.3	86.9	90.7	90.2	90.2
Sweden	90.4	90.4	90.3	81.1	81.1			
UK England	67.8	67.8	36.1	26.7	49.1	6.9	47.1	47.1
Northern and Yorkshire Cancer Registry and Information Service	81.7	81.7	26.8	23.6	92.5	0.0	65.7	65.7
West Cancer Registry	49.2	49.2	36.5	31.4	73.1	0.0	0.2	0.2
Eastern Cancer Registry and Information Centre	86.3	86.3	73.4	15.3	46.5	24.9	77.7	77.6
Queens Cancer Registry	49.0	49.0	21.4	20.8	4.3	4.3	44.8	44.8
Oxford Cancer Registry	76.6	76.6	43.2	38.8	78.8	1.9	45.1	45.1
South West Cancer Intelligence Service	72.1	72.1	33.1	29.2	36.4	13.4	51.2	51.2
West Midlands Cancer Intelligence Unit	84.0	84.0	46.3	43.0	71.4	14.9	83.4	83.4
North West Cancer Intelligence Service	63.3	63.3	31.8	23.2	30.9	10.9	9.0	9.0
UK Northern Ireland	81.5	81.5	62.8	60.4	78.7	78.7	81.0	81.0
UK Wales	6.2	6.2	4.6	4.4	58.5	58.5	20.6	20.6



Can the UK learn from elsewhere in the world?

- ICBP deliberately made use of data from some of the best intelligence systems globally;
- It has demonstrated that, beyond basic information, there is limited international consistency on recording complex variables (such as stage and treatment);
- UK standards are not always the optimum;
- Now would be the time to ensure harmonisation;
- Could the UK take the lead?

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Can the UK share with the rest of the world?

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Can the UK share with the rest of the world?

- After assessment within a population, comparison between populations becomes the lifeblood of cancer intelligence
- “We all want to understand our performance in relation to everybody else” Ciaran Devane (13/06/13)
- Much focus on within-UK (or within-England) comparisons
- Objectives of international projects such as Cancer Incidence in Five Continents, EUROCARE, CONCORD and the International Cancer Benchmarking Project provide a further key element of comparison

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The International Cancer Benchmarking Project



Objectives and scope

The ICBP is a partnership of clinicians, academics and policymakers across eight countries. It is the first of its kind, seeking to understand how and why cancer survival varies between countries.

Its objectives are:

1. Identifying specific causes of performance differences between countries with high quality cancer data, generating insights to improve cancer survival outcomes
2. Laying the foundation for an ongoing benchmarking partnership to enable the countries to track the relative successes of their reform programmes and learn from each other

The scope of the work covers primary cancers. While Module 2 seeks to gauge the beliefs and awareness towards cancer in general, Modules 3, 4 and 5 focus on four cancer sites: breast, lung, colorectal and ovarian cancer.

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Can the UK share with the rest of the world?

- To be shared, data are required in standardised format
- Data require maximum possible exposure and access
- Working assumption should be that all data (without identifiers) should be in the public domain or (at most) subject to a minimum registration process
- Try to avoid datasets restricted organisationally
- The SEER datasets represent a good working model

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National Cancer Institute U.S. National Institutes of Health | www.cancer.gov

Surveillance Epidemiology and End Results Search

providing information on cancer statistics to help reduce the burden of these diseases on the U.S. population

[Home](#) [About SEER](#) [Cancer Statistics](#) [Datasets & Software](#) [Publications](#) [Information for Cancer Registrars](#)

Cancer Statistics

Available Statistics

- [Cancer Stat Fact Sheets](#)
- [Cancer Statistics Review](#)
- [Fast Stats](#)
 - Compare Statistics:
 - [by Cancer Site](#)
 - [by Race/Ethnicity](#)
 - [by Sex](#)
 - [by Race and Sex](#)
 - [by Age At Diagnosis/Death](#)
 - [by Data Type](#)
 - [Fast Stats Help](#)
 - [Fast Stats Resources](#)
- [Cancer Query Systems](#)
- [State Cancer Profiles](#)

Resources

- [Did You Know? Video Series](#)
- [Types of Statistics](#)
- [Software Used to Generate Statistics](#)

Fast Stats

[Home](#) > [Cancer Statistics](#) > [Fast Stats](#) > by Cancer Site [Email](#) [Print Page](#) [Glossary](#)

Fast Stats

A concern was raised about the population estimates for Hispanic American Indian/Alaska Natives (AI/AN). Please see [Population Estimates for Hispanic AI/AN](#) for more details.

Compare Statistics by Cancer Site

Data Type SEER Incidence

Statistic Type Age-Adjusted Rate with 95% CI

Year Range 2000-2010 (SEER 18)

Race/Ethnicity All Races (includes Hispanic)

Sex Both Sexes

Age Range All Ages

Output ☒ Graph ☐ Table

Select Cancer Site(s) (limit 6)

<input type="checkbox"/> All Cancer Sites	<input type="checkbox"/> Female genital system	<input type="checkbox"/> Myelodysplastic syndromes (MDS)
<input type="checkbox"/> Combined	<input type="checkbox"/> Cervix Uteri	<input type="checkbox"/> Chronic myeloproliferative disorders (CMD)
<input type="checkbox"/> Bones and Joints	<input type="checkbox"/> Corpus and Uterus, NOS	<input type="checkbox"/> Chronic Myelomonocytic Leukemia (CMML)
<input type="checkbox"/> Brain & ONS	<input type="checkbox"/> Ovary	<input type="checkbox"/> Mesothelioma
<input type="checkbox"/> Brain & ONS, Benign	<input type="checkbox"/> Vagina	<input type="checkbox"/> Myeloma
<input type="checkbox"/> Breast, Female	<input type="checkbox"/> Vulva	
<input type="checkbox"/> Breast In Situ, Female		
<input type="checkbox"/> Breast, Male	<input type="checkbox"/> Gallbladder	
	<input type="checkbox"/> Hodgkin Lymphoma	<input type="checkbox"/> Oral Cavity and Pharynx
<input type="checkbox"/> Digestive system		

National Cancer Institute
U.S. National Institutes of Health | www.cancer.gov

Surveillance Epidemiology and End Results
providing information on cancer statistics to help reduce the burden of these diseases on the U.S. population

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Search

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Resources

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- [Software Used to Generate Statistics](#)

[Home](#) > [Cancer Statistics](#) > [Cancer Query Systems](#) > SEER Survival Statistics

[Email](#) [Print Page](#) [Glossary](#)

Cancer Query System: SEER Survival Statistics

Select Cancer Statistics - Table
Relative Survival by Stage (2002-2009)

Selection(s)
SEER registry = Eighteen SEER registries
Site = Stomach
Year of diagnosis = 2002-2009
Race = All races, White, Black
Sex = Male and female, Male, Female
Age at diagnosis = All ages
Stage at diagnosis = All Stages (including in situ/blanks), Localized, Regional, Distant, Unknown/unstaged

Value(s) 5 of 5 Selected [Restore Defaults](#)

☒ All Stages (including in situ/blanks)
☒ Localized
☒ Regional
☒ Distant
☒ Unknown/unstaged

[Update](#)
[Select All](#)
[Restore Default](#)

Software provided by SEER
CanQues 4.2 [<< Previous](#) [Next >>](#) [Help](#)

[Display keyboard alternatives](#) | [Place focus on applet](#) | [Help enabling Java](#)
Questions or comments to: seerweb@imsweb.com

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US Department of Health & Human Services | National Institutes of Health | National Cancer Institute | USA.gov

NORDCAN

ABOUT NORDCAN
The NORDCAN project
The NORDCAN database
The cancer dictionary
The NORDCAN group
Contacts
CANCER FACT SHEETS
-- Select a cancer --
and
-- Select a region --
GO
ONLINE ANALYSIS
Incidence/Mortality
Prevalence
Survival
GLOSSARY OF TERMS
LITERATURE
ACKNOWLEDGEMENTS
DOWNLOAD
Last update: 25.04.2013

Standardised rates by cancers (Incidence/Mortality)

Country/years*
Nordic countries
Nordic countries
Denmark
North Jutland region
Central Jutland region
Southern Denmark region
The capital region
Zealand region
Faroe islands
Finland
Region Helsinki
Region Kuopio
Region Oulu
Region Tampere
Region Turku
Iceland
Reykjavik-Reykjanes
Outside the capital
Norway
Central region
Northern region

2010
2009
2008
2007
2006

Type
Incidence
Mortality

Age range
from to
0- 85+

Output
☐ Text file
☐ PDF file

[Execute](#)

Nordic countries (2010)
Incidence, Male, age 0-85+

Cancer	Numbers	Crude Rate	ASR (W)	ASR (E)	ASR (N)	Cumulative Risk
Acute leukaemia	597	4.7	3.9	4.2	4.9	-
All sites but non-melanoma skin cancer	71280	563.3	303.6	440.9	574.0	-
Bladder etc.	4871	38.5	18.5	28.8	41.1	-
Bone	122	1.0	0.9	0.9	0.9	-
Brain, central nervous system	2051	16.2	11.4	14.2	16.0	-
Breast	103	0.8	0.4	0.6	0.9	-
Colon	5471	43.2	21.1	32.6	46.0	-
Colorectal	8933	70.6	35.3	53.8	74.1	-
Eye	163	1.3	0.8	1.1	1.3	-
Gallbladder	415	3.3	1.7	2.5	3.4	-
Hodgkin lymphoma	337	2.7	2.4	2.6	2.6	-
Kidney	2108	16.7	9.5	13.4	16.5	-
Larynx	587	4.6	2.5	3.7	4.6	-

What can others learn from the UK?

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What can others learn from the UK?

- Much underlying common practice (reflected in training)
 - Where, how and from whom to identify new cases
 - How to obtain information about cases
 - Data items to collect and how to code them
 - Basic rules (date of diagnosis, multiple primary)
- The UK has a highly skilled cancer registration workforce with lots of experience in data collection (both the formal and informal aspects)
- The UK, through UKACR, has put in place well designed training material and programmes for staff development
- Can this experience be shared internationally?

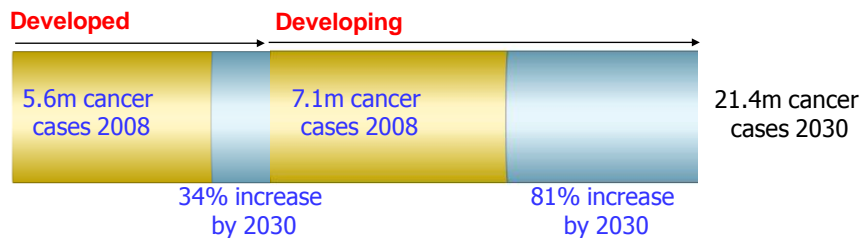
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The worldwide burden of cancer 2030*

- Approx. **21.4 million** new cases will be diagnosed in **2030** - up 69% from 12.7 million in 2008

*assuming no change in risk from 2008



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GLOBOCAN 2008
Cancer Incidence and Mortality Worldwide

A global initiative for cancer registries

- Inequity in the cancer burden and our surveillance of the burden between developed and developing world
- Wide recognition that the collection of basic registration information is not a luxury, but a cost-effective investment to guide cancer control planning
- Momentum through UN Political Declaration on Non-Communicable Diseases (2011) and WHO Global Action Plan (2012) and Disease Monitoring Framework (2013)
- Cancer Incidence now a global WHO indicator
- Strong alliance of partners with shared objectives

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World Health Organization

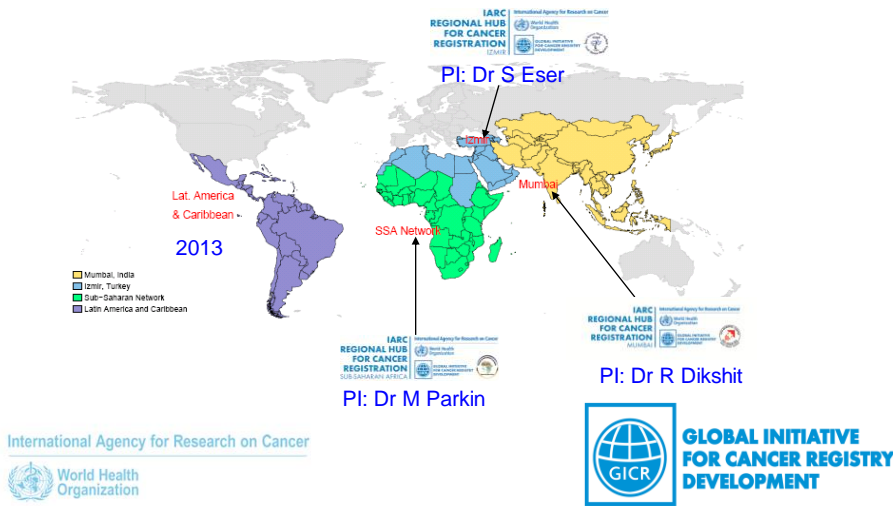


International Association of Cancer Registries



IARC Regional Hubs for cancer registration

Technical support Training Research Advocacy & Networking



GICR: early results

- **Two hubs initiated in 2012:** Mumbai (India) and the Network for Sub-Saharan Africa
- **Two hubs to become operational in 2013:** Izmir (Turkey) and in South America
- **Technical support and training** to implement CanReg5, basic cancer epidemiology and principles of cancer registration
- **Collaborative research agreements**, mapping and situation analyses of hub catchment areas, peer-reviewed articles pending
- **Advocacy** high-level communications and policy briefs in international fora and with national authorities
- **\$1+ million** raised to date from IARC and UICC members and partners



GLOBAL INITIATIVE FOR CANCER REGISTRY DEVELOPMENT

GICR: next priorities

- Fulfillment of funding objectives
 - **\$15m for 2014-2018**
- Strengthening of GICR alliance – new sectors (private and philanthropic)
- Building for full operation of six regional hubs
- Advocacy to make the case for sustainable cancer registries
- Modern education and training programme with north-south mentoring partnerships



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GLOBAL INITIATIVE
FOR CANCER REGISTRY
DEVELOPMENT

What can others learn from the UK?

- Five UK Contributions

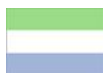
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Wales – Sierra Leone twinning initiative in Cancer Registration

Welsh Assembly
WCISU
Velindre Cancer Link
Sierra Leone Cancer Trust
IARC



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The NICR Staging Tool The way forward

Breast

Extension to chest wall (not including only pectoralis muscle)	T4c <input checked="" type="radio"/> Yes <input type="radio"/> No
Inflammatory carcinoma	<input type="radio"/> Yes <input checked="" type="radio"/> No
Enter size of invasive tumour (cm)	0.1
Ulceration/ipsilateral satellite nodules/oedema (incl. peau d'orange) of skin	<input checked="" type="radio"/> Yes <input type="radio"/> No
Number of positive axillary nodes (at least one deposit >2.0mm)	N1a 1
Metastases in intraclavicular nodes	<input type="radio"/> Yes <input checked="" type="radio"/> No
Metastases in clinically detected internal mammary nodes	<input type="radio"/> Yes <input checked="" type="radio"/> No
Metastases in internal mammary nodes with metastases in sentinel lymphnode (not clinically detected)	<input type="radio"/> Yes <input checked="" type="radio"/> No
Micrometastases only: none >2.0mm (but: >0.2mm or more than 200 cells)	<input type="radio"/> Yes <input checked="" type="radio"/> No
Metastases in supraclavicular nodes	<input type="radio"/> Yes <input checked="" type="radio"/> No
Distant metastases	M1 Distant metastases
TNM	T4cN1aM1
Calculate	

NICR Staging Tool

Licensed to IARC Summer School Ver. 2.7.2

Breast

Bladder

Lung

Lymphoma

Prostate

Skin melanoma

Gynae

Digestive system

Designed by Dr Lisa Ranaghan and Mr Giulio Napolitano, NI Cancer Registry



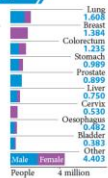
World cancer factsheet

August 2012

World cancer burden (2008)

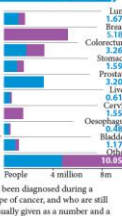
Incidence

Cancer is a leading cause of disease worldwide. An estimated 12.7 million new cancer cases occurred in 2008. Lung, female breast, colorectal and stomach cancers accounted for 40% of all cases diagnosed worldwide. In men, lung cancer was the most common cancer (16.5% of all new cases in men). Breast cancer was by far the most common cancer diagnosed in women (23% of all new cases in women)¹.



Prevalence

Almost 29 million people diagnosed with cancer within the five years previously were alive at the end of 2008. Most were women after their breast cancer diagnosis (5.2 million), men and women after their colorectal cancer diagnosis (3.3 million), and men after their prostate cancer diagnosis (3.2 million)¹⁻³.

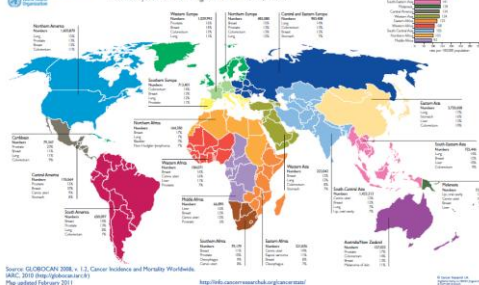


The Prevalence of a particular cancer is the number of persons in a defined population who have been diagnosed during a fixed time in the past with that type of cancer, and who are still alive at the end of a given year. Usually given as a number and a

People 4 million 8m

Cancer Incidence Worldwide

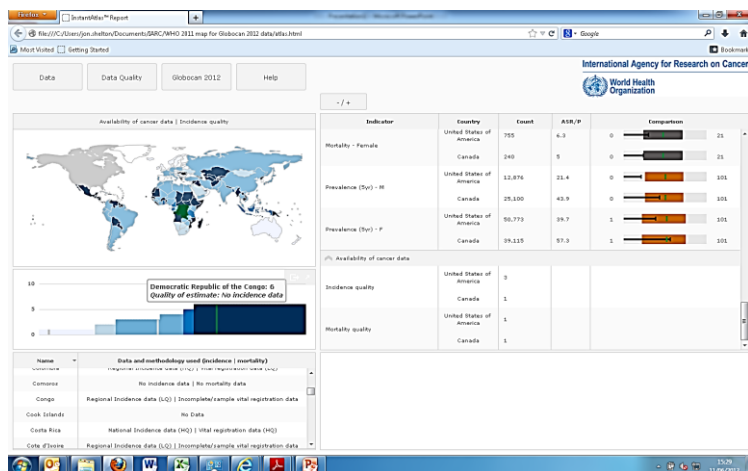
Breakdown of the estimated 12.7 million new cases. World-age standardised incidence rates and the most commonly diagnosed cancers by the different regions of the world, 2008.

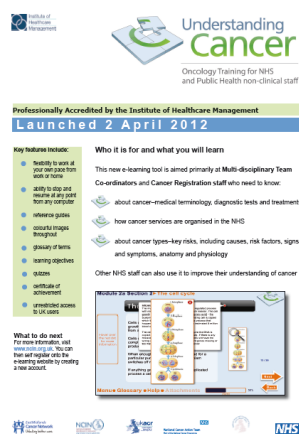


Source: GLOBOCAN 2008, v. 1.1. Cancer Incidence and Mortality Worldwide. IARC, 2010 (http://globocan.iarc.fr). The updated February 2011.

http://info.cancerresearchuk.org/press/

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World Cancer
Leaders' Summit

2013

18-19 November | Cape Town, South Africa
Closing the Cancer Divide
by 2025

Background Information

- Date: **18-19 November**, Cape Town, South Africa, Mount Nelson Hotel and Cape Town City Hall
- Organised in partnership with the CANSA, Department of Health of South Africa, IARC, IAEA, WHO
- **Summit Theme:** *Closing the Cancer Divide by 2025*. Analysis of disparities in cancer control within and across national, international and regional boundaries. Particular focus on women's cancers **and the need for improved cancer registries**.
- Attendance – A maximum 170 participants with emphasis on heads of state, cancer CEOs, select group of health and finance ministers, foundation CEOs, Corporate CEOs, development agency Directors.
- Summit Ambassador – FL of Zambia Dr Christine Kaseba Sata