



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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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:

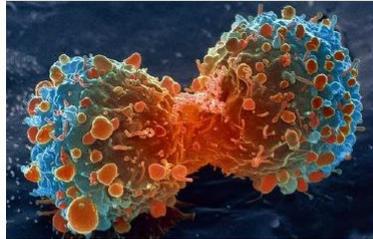
- Collect, analyse and disseminate information on the global burden of cancer
 - Cancer Incidence in Five Continents
 - International Incidence of Childhood Cancer
 - GLOBOCAN
- Support capacity building programmes for cancer registries worldwide, especially in low and middle-income countries
- Conduct 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 Rosa Silverman
6:00AM BST 12 Jun 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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- 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 Mairinge¹, John Butler², James D. Brierley³, Bernard Rachet¹ and Michel P. Coleman¹

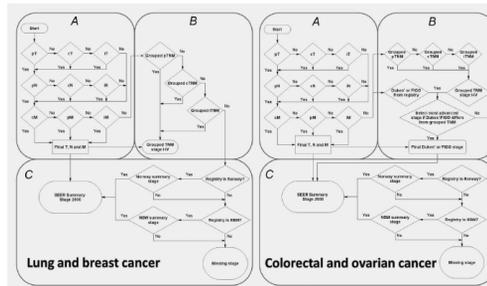
¹ Cancer Research UK Cancer Survival Group, Department of Non-Communicable Disease Epidemiology, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom

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

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

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

Jurisdiction	Cancer and period of diagnosis							
	Collection 2000-2007		Lung 2006-2007		Breast 2000-2007		Ovary 2006-2007	
	Dukes ^b	SEER	TNM	SEER	TNM	SEER	RIGN	SEER
New South Wales	96.6		77.2		92.1		96.3	
Victoria	7.6	7.6	0.0	0.0	7.4	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	88.5	87.5	90.5	90.5
Ontario ^c	81.6	81.6	75.7	59.0	89.1	53.4	68.7	68.7
Denmark ^d	78.8	78.9	89.2	89.2	88.7	88.7	77.2	77.2
Norway		90.4		90.5	87.3	86.9	90.7	90.2
Sweden	95.6	94.4	94.3	94.3	83.1	83.1		
UK England	67.8	67.8	38.1	26.7	49.1	8.9	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	60.2	60.2	36.5	33.4	73.1	0.0	0.2	0.2
Eastern Cancer Registry and Information Centre	86.3	86.3	73.4	35.3	65.5	24.9	77.7	77.6
Thames Cancer Registry	49.0	49.0	23.4	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	48.1	48.1
South West Cancer Intelligence Service	72.1	72.1	31.1	29.2	34.6	33.6	31.2	31.2
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	62.0	60.4	78.7	78.7	81.0	81.0
UK Wales	6.2	6.2	4.6	4.4	58.5	54.5	50.6	50.6



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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

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

Home > Cancer Statistics > Fast Stats > by Cancer Site

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)

All Cancer Sites Combined

Bones and Joints

Brain & ONS

Brain & ONS, Benign

Breast, Female

Breast In Situ, Female

Breast, Male

Digestive system

Female genital system

Cervix Uteri

Corpus and Uterus, NOS

Ovary

Vagina

Vulva

Gallbladder

Hodgkin Lymphoma

Myelodysplastic syndromes (MDS)

Chronic myeloproliferative disorders (CMD)

Chronic Myelomonocytic Leukemia (CMML)

Mesothelioma

Myeloma

Oral Cavity and Pharynx

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](#)

Resources

- [Cancer Query Systems](#)
- [State Cancer Profiles](#)
- [Did You Know? Video Series](#)
- [Types of Statistics](#)
- [Software Used to Generate Statistics](#)

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

Home About SEER Cancer Statistics Datasets & Software Publications Information for Cancer Registrars

Home > Cancer Statistics > Cancer Query Systems > SEER Survival Statistics

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

Value(s) 5 of 5 Selected **Restore Defaults**

All Stages (including insitu/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

This Web site is a service of [Surveillance Research Program, NCI](#) [Site Map](#) | [Accessibility](#) | [Policies](#) | [FOIA](#) | [File Formats](#) | [Contact Us](#)

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

NORDCAN

Standardised rates by cancers (Incidence/Mortality)

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 --

ONLINE ANALYSIS
 Incidence/Mortality
 Prevalence
 Survival

GLOSSARY OF TERMS
 LITERATURE
 ACKNOWLEDGEMENTS
 DOWNLOAD

Last update: 25.04.2013

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?

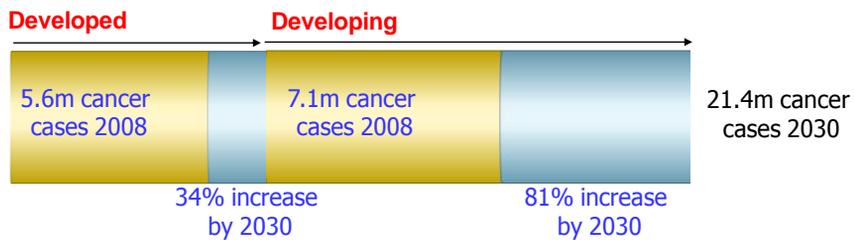
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The worldwide burden of cancer 2030*

- 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



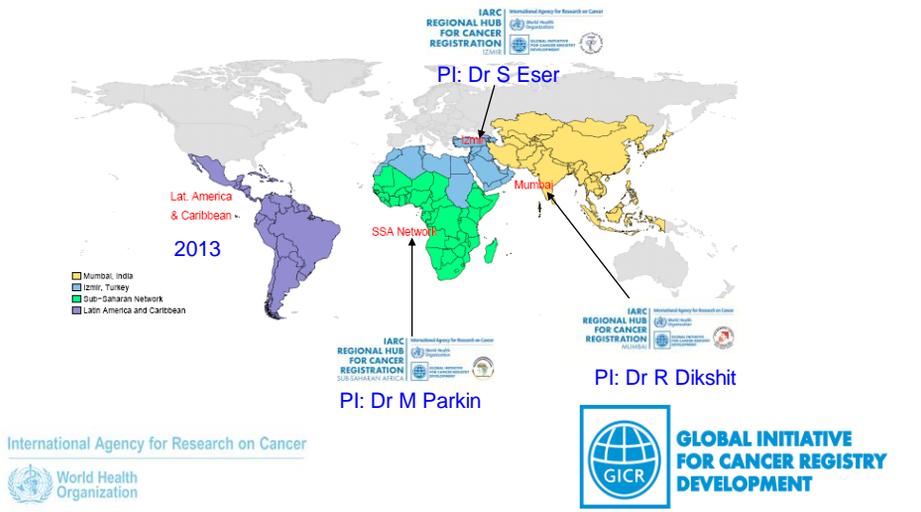
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GLOBAL INITIATIVE FOR CANCER REGISTRY DEVELOPMENT

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



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

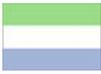
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Wales – Sierra Leone twinning initiative in Cancer Registration

Welsh Assembly
 WCISU
 Velindre Cancer Link
 Sierra Leone Cancer Trust
 IARC



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The NICR Staging Tool

The way forward

Breast		T4c
Extension to chest wall (not including only pectoralis muscle)	<input checked="" type="radio"/> Yes <input type="radio"/> No	<input checked="" type="radio"/> Yes <input type="radio"/> No
Inflammatory carcinoma	<input type="radio"/> Yes <input checked="" type="radio"/> No	<input type="radio"/> Yes <input checked="" type="radio"/> No
Enter size of invasive tumour (cm)	0.1	0.1
Ulceration/ipsilateral satellite nodules/oedema (incl. peau d'orange) of skin	<input checked="" type="radio"/> Yes <input type="radio"/> No	<input checked="" type="radio"/> Yes <input type="radio"/> No
N		N1a
Number of positive axillary nodes (at least one deposit >2.0mm)	1	1
Metastases in infraclavicular nodes	<input type="radio"/> Yes <input checked="" type="radio"/> No	<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	<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	<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	<input type="radio"/> Yes <input checked="" type="radio"/> No
Metastases in supraclavicular nodes	<input type="radio"/> Yes <input checked="" type="radio"/> No	<input type="radio"/> Yes <input checked="" type="radio"/> No
M		M1
Distant metastases	Distant metastases	Distant metastases
TNM	T4cN1aM1	T4cN1aM1
Calculate		

NICR Staging Tool Ver. 2.7.2

Licensed to IARC Summer School

Breast

Bladder

Lung

Lymphoma

Prostate

Skin melanoma

Gynae

Digestive system

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

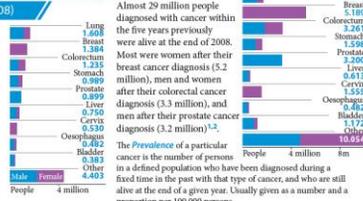


World cancer factsheet

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).



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).^{1,2}

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

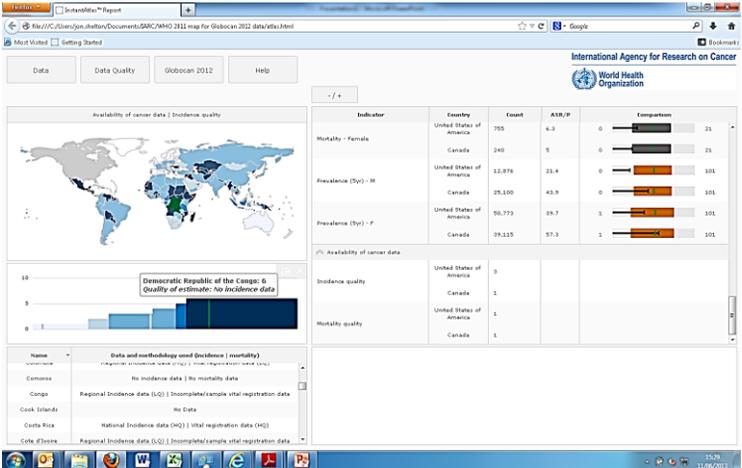
People 4 million 8m

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).
Fig updated February 2011





Understanding Cancer 
e-learning
 Oncology training for NHS
 non-clinical staff



Professionally Accredited by the Institute of Healthcare Management
Launched 2 April 2012

Key features include:

- Health to work at your own pace from work or home
- Ability to stop and resume at any point that is convenient
- Reference guides
- Account topics throughout
- Glossary of terms
- Learning objectives
- Quizzes
- Certificate of achievement
- Unlimited access to all users

Who it is for and what you will learn

This new e-learning tool is aimed primarily at Multi-disciplinary Team Co-ordinators and Cancer Registration staff who need to know:

- about cancer-medical terminology, diagnostic tests and treatments
- how cancer services are organised in the NHS
- about cancer types-key risks, including causes, risk factors, signs and symptoms, anatomy and physiology

Other NHS staff can also use it to improve their understanding of cancer

What to do next
 For more information, visit www.understandingcancer.org.uk or email info@understandingcancer.org.uk or call 020 7096 1111. You will then self register into the e-learning system by creating a new account.




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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