



Cancer Registration

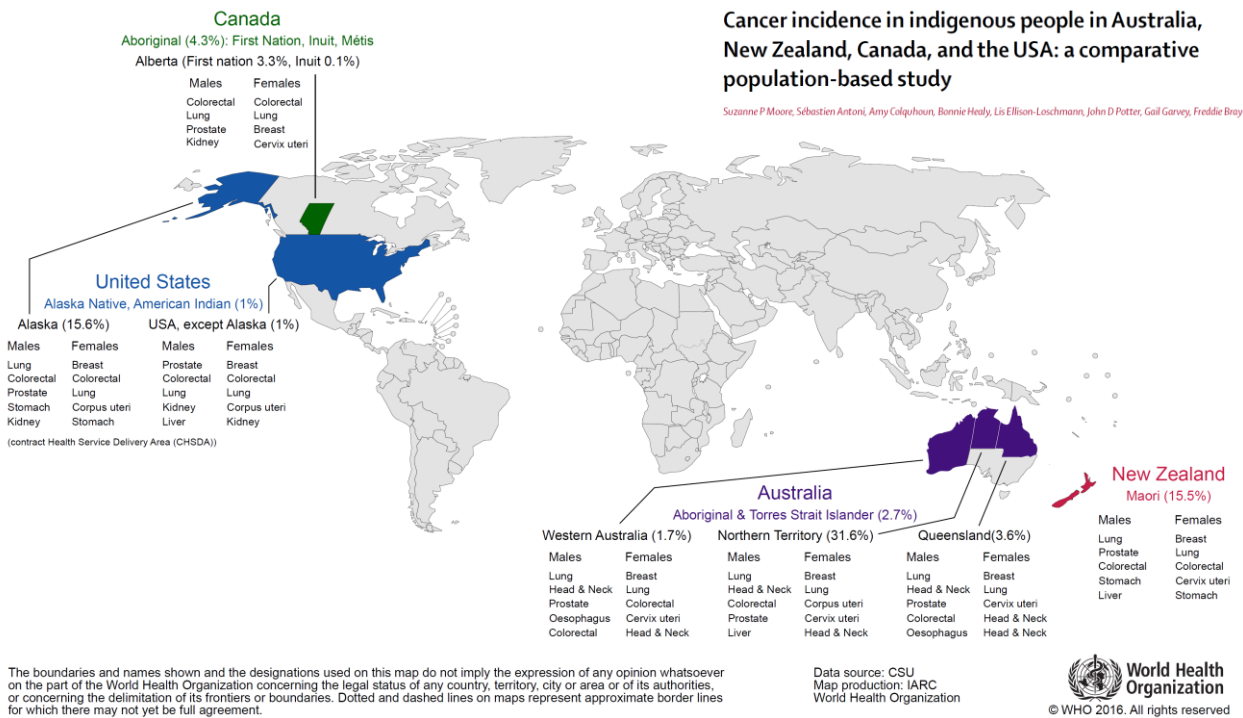
Freddie Bray • Section of Cancer Surveillance
International Agency on Research on Cancer

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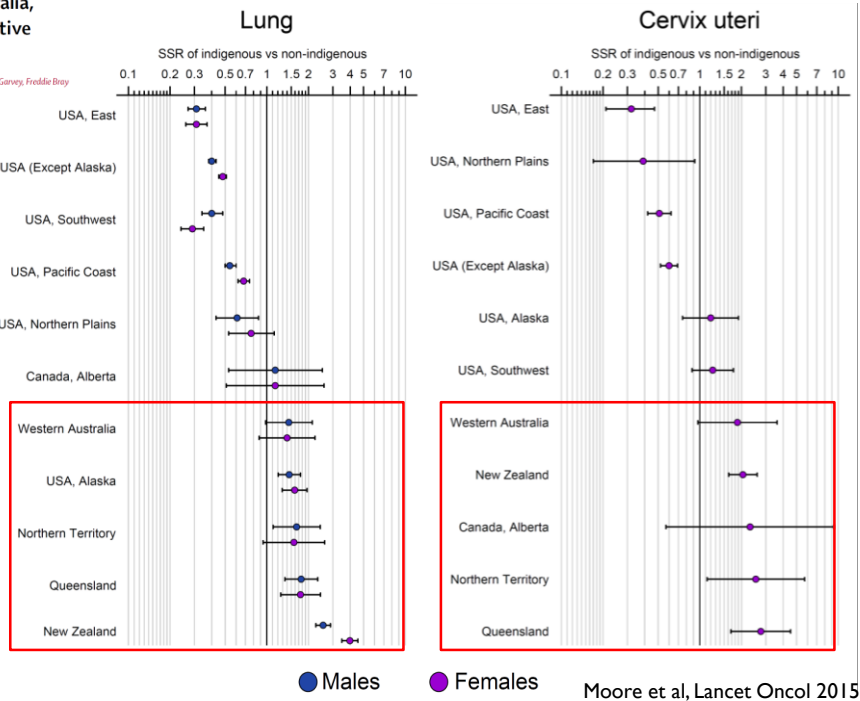
12 April 2016

- ① Rationale
 - Why invest in population-based cancer registration worldwide?
- ② The Global Initiative for Cancer Registry Development (GICR)
- ③ Activities and Progress



Cancer incidence in indigenous people in Australia, New Zealand, Canada, and the USA: a comparative population-based study

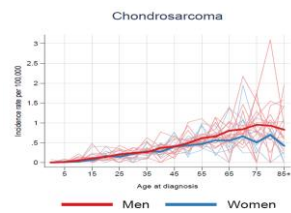
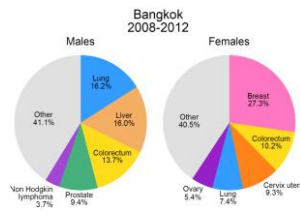
Suzanne P Moore, Sébastien Antoni, Amy Colquhoun, Bonnie Healy, Lis Ellison-Loschmann, John D Potter, Gail Garvey, Freddie Bray



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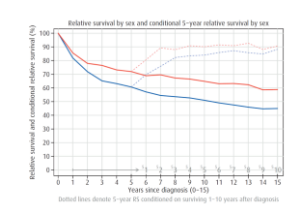
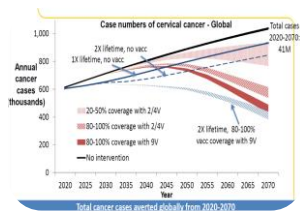


Cancer registration – a foundation for cancer control



Describing
occurrence

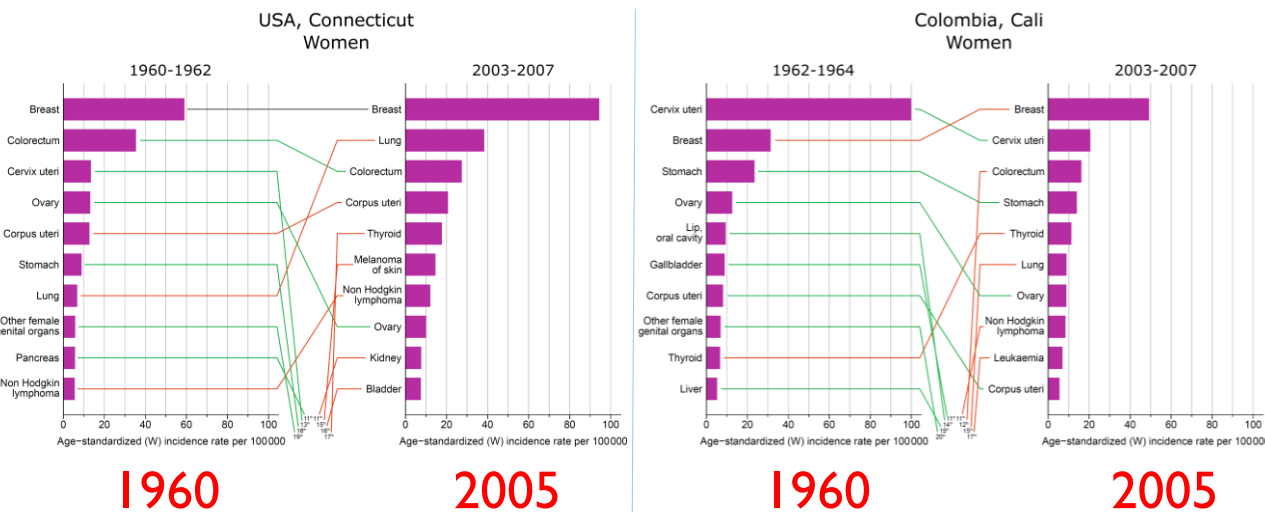
Understanding
causation



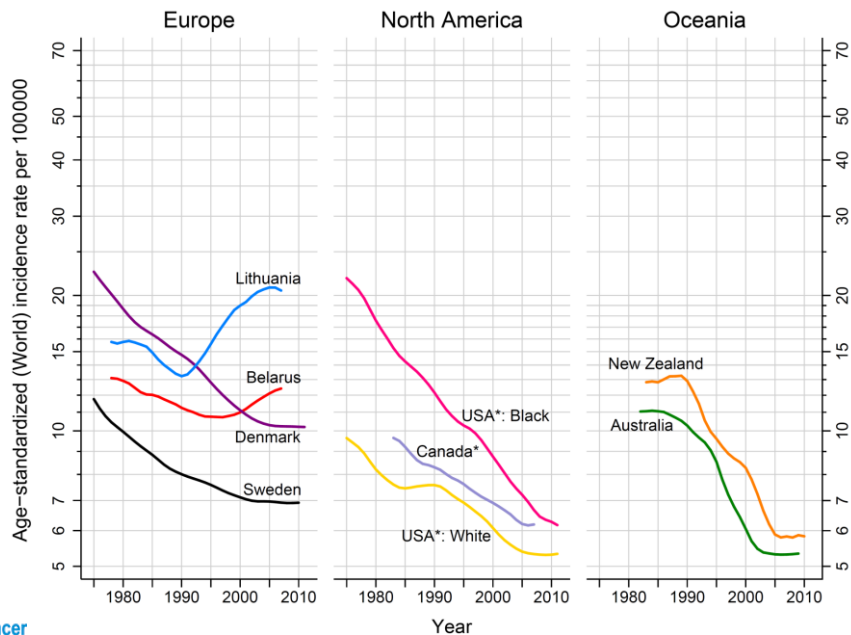
Evaluating
prevention

Planning
cancer care

Ten Volumes of *Cancer Incidence in Five Continents*



Cervical cancer incidence 1975-2010



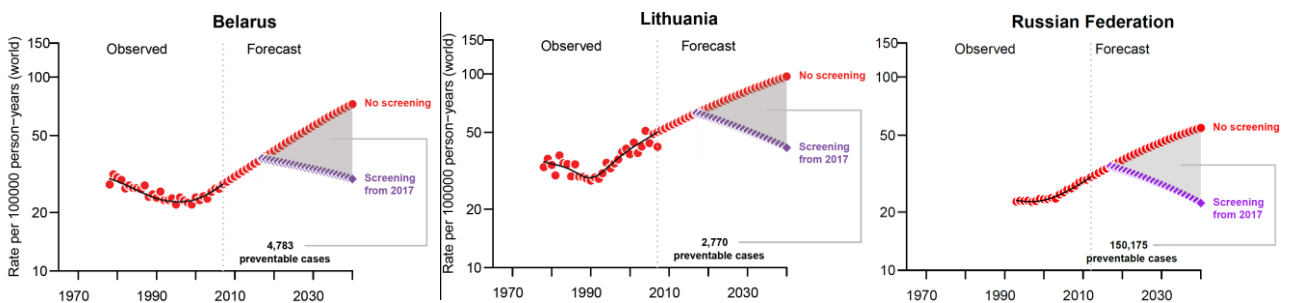
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<http://ci5.iarc.fr>

Cervical cancer incidence: observed & forecasted 1980-2040

- Impact of no intervention vs. effective screening beginning 2017



- Effective screening implementation: a 50-60% reduction of the projected rates circa 2040
- Prevention of cervical cancer in 1,500 women in Estonia to over 150,000 women in the Russian Federation.

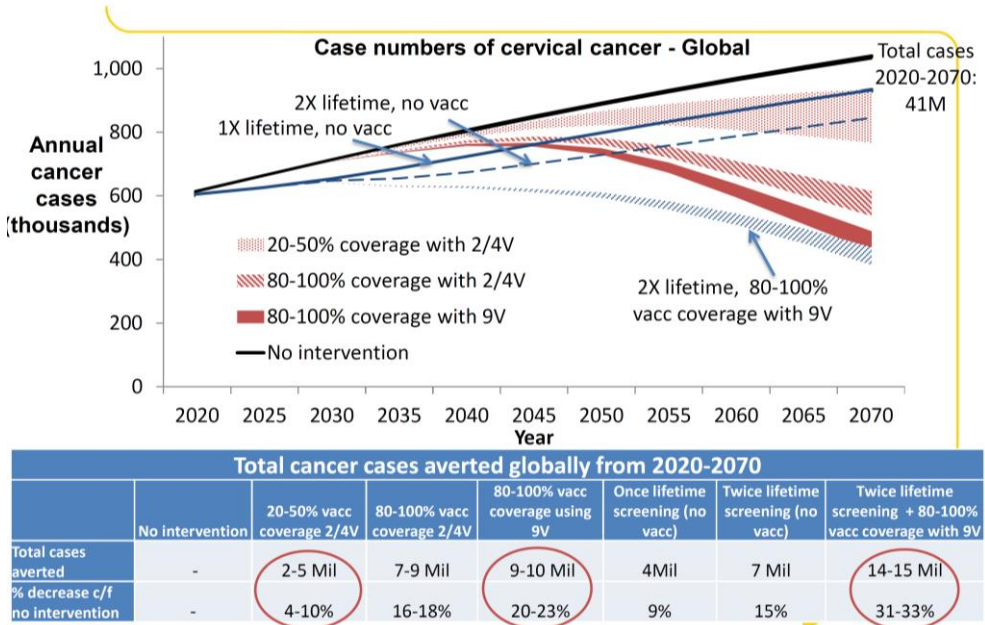
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Vaccarella et al, submitted

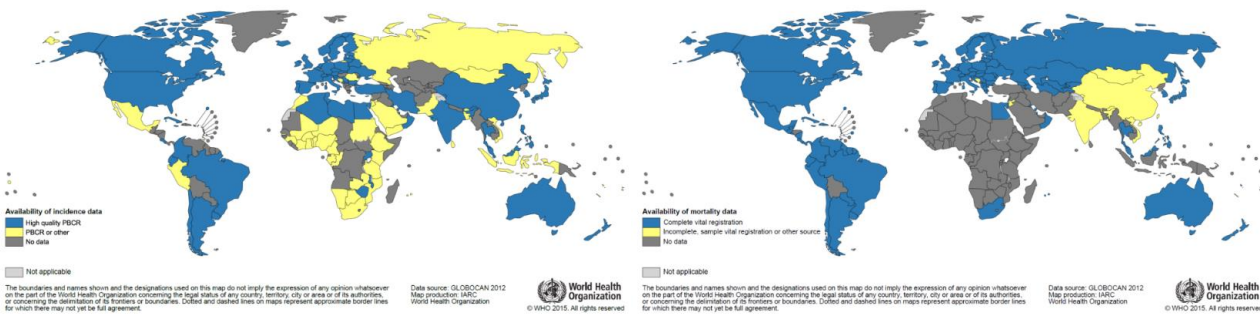
The projected global burden of cervical cancer to 2070

Combining vaccination and screening initiatives successfully could prevent over 10 million cervical cancers globally in the next 50 years.



Simms and Canfell, in preparation.

Data availability by country worldwide



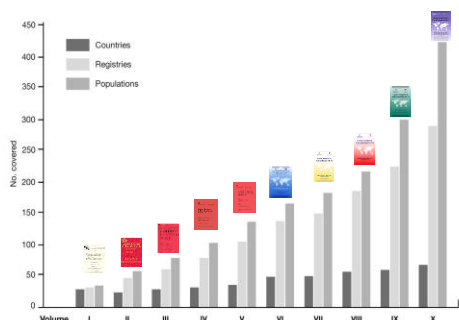
INCIDENCE **36%**

Only 67 of 184 countries report high quality incidence data to IARC¹

MORTALITY **19%**

Only 34 of 178 countries report high quality mortality data to WHO²

¹ Cancer Incidence in Five Continents Volume X
² WHO Mortality Database



Coverage in ten volumes of
Cancer Incidence in Five Continents

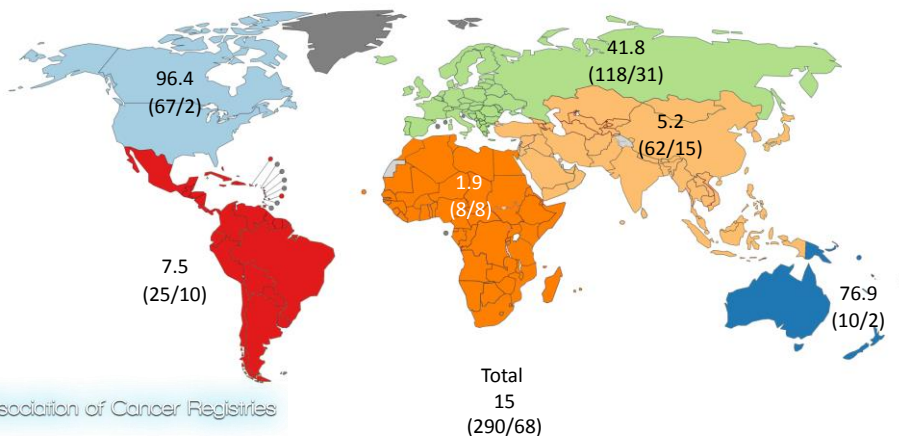
	% of regional population represented		
	Volume I ≈1965	Volume V ≈1985	Volume X ≈2005
Africa	0.4	0.0	1.9
Asia	0.3	2.0	5.7
C/S America	5.1	4.9	7.5
<hr/>			
Europe	7.3	17.0	41.7
Oceania	19.4	83.0	77.8
N America	7.8	28.2	94.7
TOTAL	2.6	6.3	14.3

Coverage in ten volumes of
Cancer Incidence in Five Continents by region

High quality data availability by population worldwide

Cancer Incidence in Five Continents (CI5)

% of the population covered (Vol. X around 2005)
(number of registries/number of countries)



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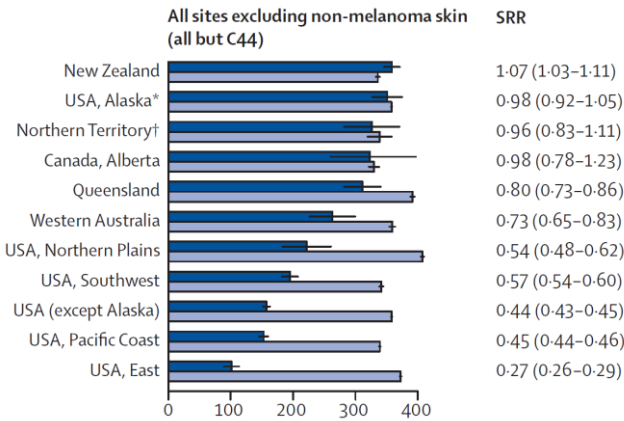
Map production: IARC
World Health Organization



Equitable cancer control: better data needed for indigenous people

Published Online
October 15, 2015
[http://dx.doi.org/10.1016/S1470-2045\(15\)00295-8](http://dx.doi.org/10.1016/S1470-2045(15)00295-8)
See Articles page1483

“Most countries rely on a method in which **indigenous status** is measured differently in the cancer and census data, resulting in a numerator-denominator bias that most likely underestimates cancer incidence in indigenous people.”



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Sarfati and Robson, Lancet Oncol 2015



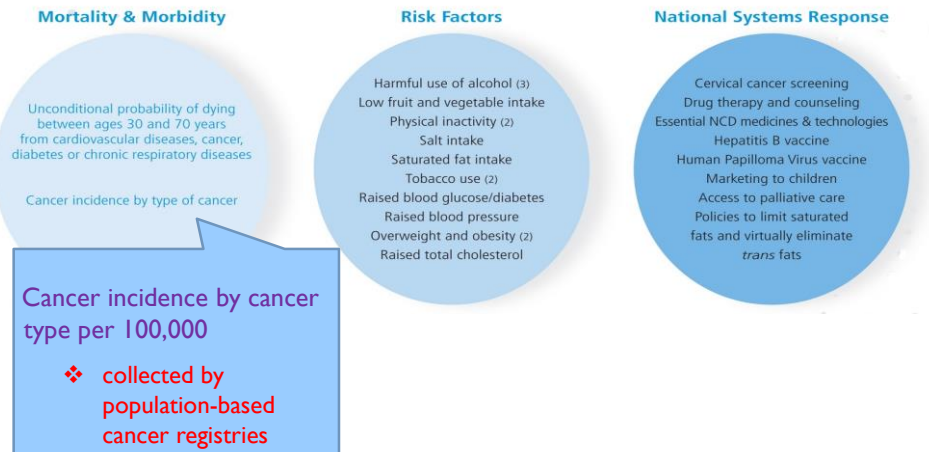
By 2025, a 25% relative reduction in risk of cardiovascular diseases, cancer, diabetes, or chronic respiratory diseases



Target 3.4. By 2030, reduce by one-third premature mortality from NCDs through prevention and treatment and promote mental health and well-being.

Global Monitoring Framework

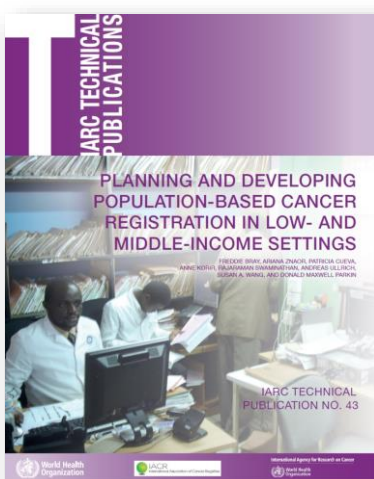
25 indicators



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IARC Technical Publication No. 43



- A joint IACR-IARC publication
- Developed with WHO with financial support from the GAVI Alliance
- Provides technical advice to planners and health specialists in LMICs wishing to plan/develop population-based cancer registries (PBCR):
 - Role and status of PBCRs worldwide
 - Planning and developing PBCRs
 - Sources of information
 - Quality control
 - Reporting the results

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http://www.iarc.fr/en/publications/pdfs-online/treport-pub/treport-pub43/IARC_Technical_Report_No43.pdf

Cancer registries in Africa 2014: A survey of operational features and uses in cancer control planning

Robai Gakunga¹ and D. Maxwell Parkin²; On behalf of the African Cancer Registry Network*

¹ Consultant, African Cancer Registry Network (ACRN), INCIR, Prama House, 267 Banbury Road, Oxford, OX2 7HT, United Kingdom

² Honorary Senior Research Fellow, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Old Road Campus, Roosevelt Drive, Oxford, OX3 7LF, United Kingdom

A questionnaire survey of all active population based cancer registries in sub-Saharan Africa obtained information on their characteristics (size, staffing, funding), methods of working, the nature of any links between registries and their respective Health Authorities (national and/or local), and the use of their data in research or cancer control planning. 23/25 registries (92%) responded. Sources of direct funding and estimated amounts from each source were established, and suggest that it is approximately US\$8-9 per case registered. Almost half of the funding is used for routine data collection, processing and analysis. Staffing levels vary, partly as a function of the registry size (approximately one FTE per 300 cases registered). Most data collection is active, using multiple sources (median 10 per registry), and is largely paper-based (abstraction onto paper forms), although all use the computer system CanReg[®] for data entry, storage and analysis. Most reporting by the registries is remarkably timely, and in general, their results are widely used by health authorities and other stakeholders in planning and evaluating services, while research output is much more variable. These registries are the source of almost all the existing information on cancer incidence and mortality in sub-Saharan Africa, as published in IARC's "Globocan".

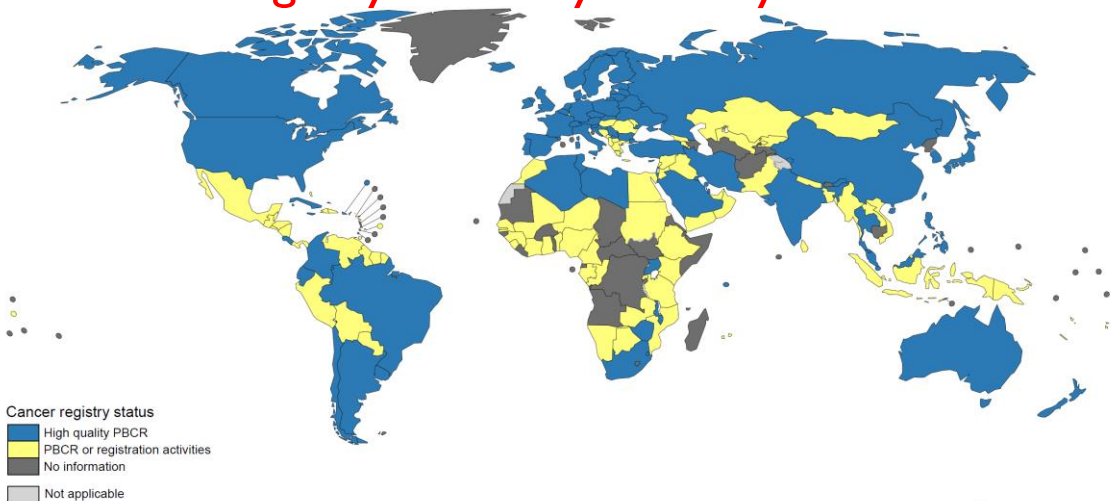
Special Section Paper

'Sources of direct funding and estimated amounts from each source were established, and suggest that it is approximately US\$8-9 per case registered.'

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Cancer registry status by country worldwide



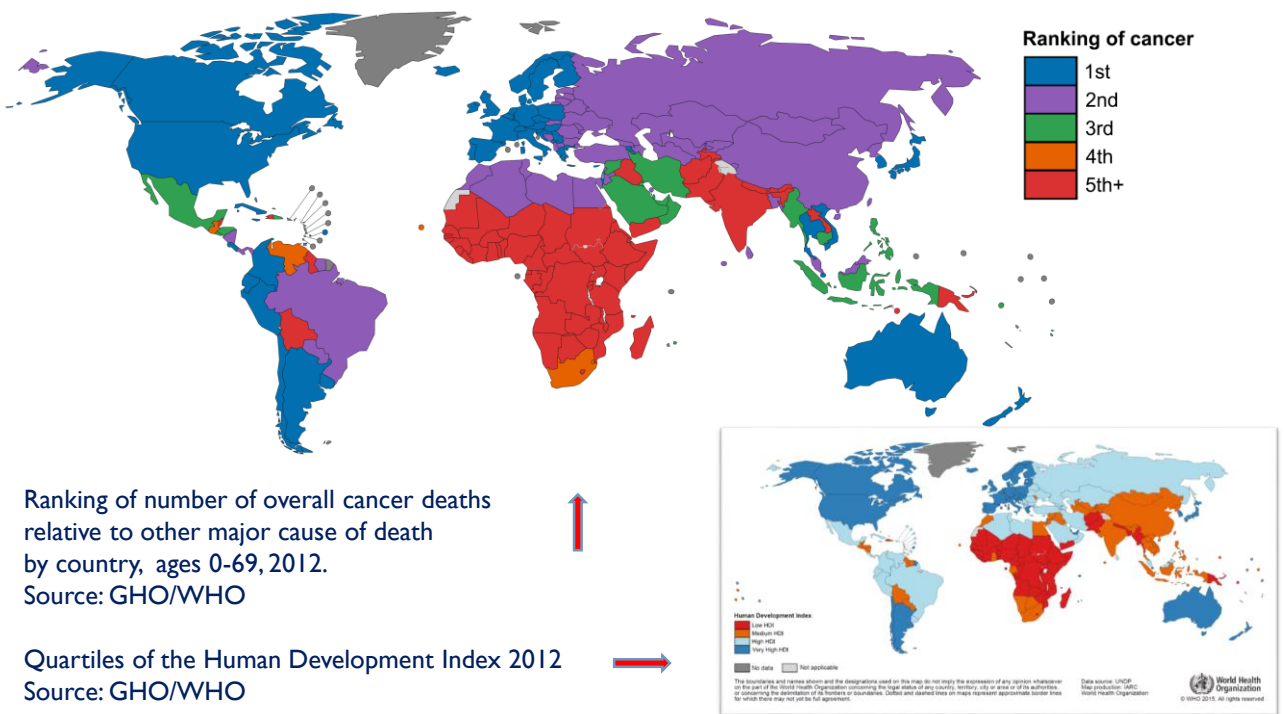
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Data source: GICR
Map production: IARC
World Health Organization

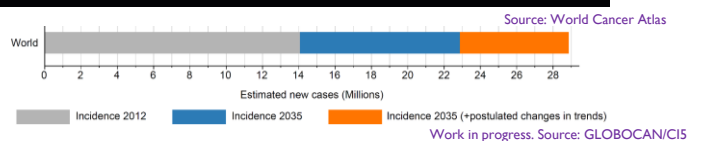
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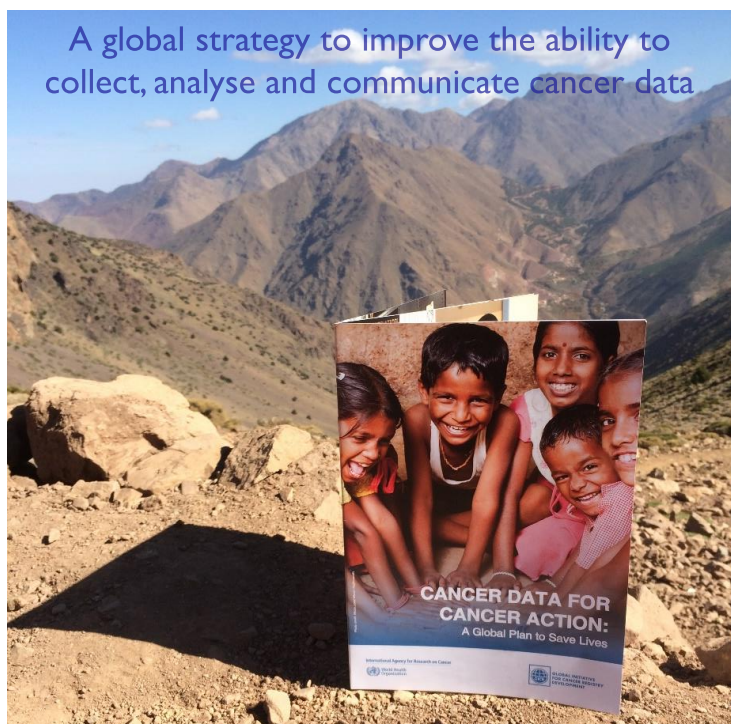
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Data for Action



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National Cancer Institute
at the National Institutes of Health



International Association of Cancer Registries



INCTR
International
Network
for Cancer Treatment and Research



and other national and international partners



Strengthening Cancer Control: the GICR



A process to improve in-country capacity to collect, analyse and communicate cancer data

- Phased objectives through IARC Regional Hubs to target 20 LMIC by 2020 and a further 30 by 2025

Global Coordination:

- An official tool to support governments to achieve reporting on the Global Monitoring Framework
- Integration of plans with key international organizations
- Development of Mentorship, Training, Best Practices and Electronic platforms
- Indicators to monitor progress



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GLOBAL INITIATIVE FOR CANCER REGISTRY DEVELOPMENT

<http://gicr.iarc.fr>



STRATEGIC GOALS

- 1 Country leadership
- 2 Regional Focus
- 3 Global Coordination

FOUNDATION

PRINCIPLES

- Country led cancer action
- Focused on low– and middle– income countries
- Collaborative, flexible model
- Scientific integrity
- Results-based management

CORE FUNCTIONS

- Training
- Directed Support
- Cancer Control
- Networks

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OUTCOMES

Long-Term:

- 50 new high quality cancer registries by 2025
- Evidence base for cancer control planning
- Greater understanding of the cancer burden

Medium-Term:

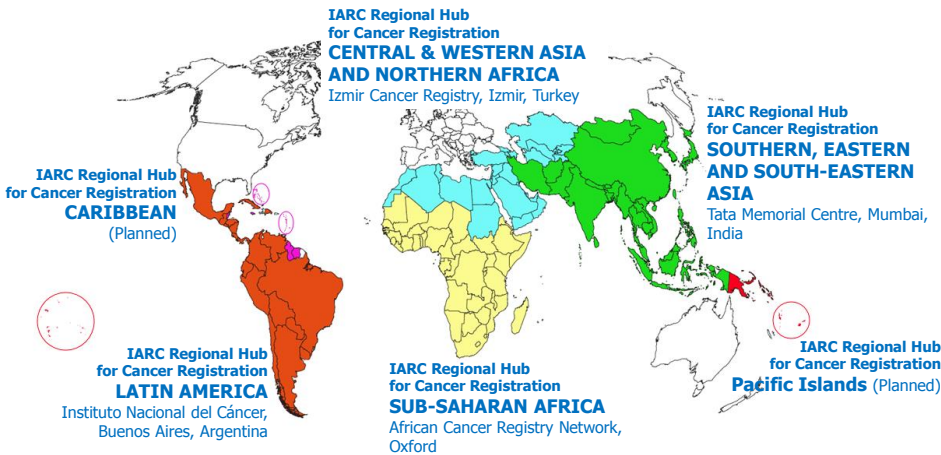
- First cancer registry reports in 50 countries
- Regional and national cancer registry networks
- Accelerate the development of new free and open-sourced electronic tools

Short-Term:

- 50 country led plans to implement population based cancer registries
- Training for over 700 professionals
- Development of mentorship programme



Six IARC Regional Hubs for Cancer Registration



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- Promote international standards
- Flexible tool to match local context and needs
- Create linkages with partner initiatives to provide bigger impact

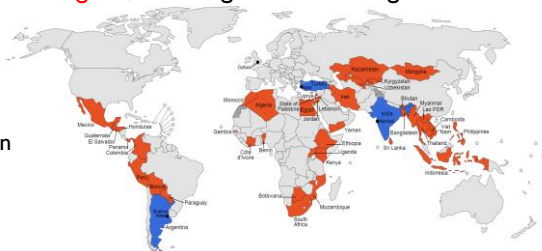
Table 1. GICR IARC Regional Hubs

Principal Investigator	Year Established	Area of Coverage	Main Collaborators
Dr. Rajesh Dikshit Tata Memorial Hospital	2012	Southern, Eastern and South-Eastern Asia	Tata Memorial Hospital (Mumbai, India)
Dr. Max Parkin University of Oxford	2012	Sub-Saharan Africa	African Cancer Registry Network, International Network for Cancer Treatment and Research
Dr. Sultan Eser Izmir Cancer Registry	2013	Northern Africa, Central and Western Asia	Cancer Control Department (Ministry of Health Turkey), NCI Centre for Global Health (US National Cancer Institute)
Dr. Graciela Abriata National Cancer Institute (Argentina)	2014	Latin America	National Cancer Institute (Buenos Aires, Argentina), Brazil National Cancer Institute (Rio de Janeiro, Brazil), Colombia National Cancer Institute (Bogota, Colombia), Uruguay Cancer Registry – Honorary Commission for the Fight Against Cancer (Montevideo, Uruguay), Red de Institutos Nacionales de Cáncer (RINC)



The GICR: regional and country level activities 2014–15

- **36 consultancies were completed** to assess the current status of cancer registration and the potential for change
 - Sub-Saharan Africa (10), Caribbean (4), Izmir- N.Africa/W.Asia (6), Latin America (10) and Mumbai- S. E & SE Asia (6)
- **28 GICR-led or affiliated regional courses were delivered.** In 2016:
 - Launch of regional expert training: CanReg5 Master Class (January)
 - Development of online learning tools
- **17 agreements with countries were signed**, including 3 collaborating centres in Latin America
- **Launch of Regional Advisory Committees**
 - Sub-Saharan Africa, Izmir, Latin America and Mumbai



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Not applicable

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Data source: GICR
Map production: IARC
World Health Organization

World Health Organization
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GICR – activities by region 2014-15

Activity	Total Number	Region [number] ¹		
		Africa	Asia	Latin America
Site visits ²	36	Angola, Algeria, Egypt, Gambia, Madagascar, Malawi, Mali, Morocco, Namibia, Reunion, Senegal, Uganda, Zimbabwe [13]	Cambodia, India, Indonesia, Iran (Islamic Republic of), Kyrgyzstan, Laos People's Democratic Republic, Philippines, Turkey, West Bank and Gaza Strip [9]	Argentina, Costa Rica, El Salvador, Honduras, Guatemala, Mexico, Nicaragua, Panama, Paraguay, Peru [10]
Courses	28	Cote d'Ivoire (Abidjan, August 2014); Egypt (Cairo, September 2014); Ethiopia (Addis Ababa, August 2015); Guinea (Conakry, August 2014); Kenya (Eldoret, March 2015); Kenya (Nairobi, August 2015); Mozambique (Beira, July 2014); Mozambique (Maputo, July 2014); Namibia (Windhoek, June 2014); Namibia (Windhoek, February 2015); Sudan (Khartoum, November 2014); Uganda (Kampala, June 2014) [12]	Cambodia (Phnom Penh, February 2014); China (Shanghai, September 2014); India (Chennai, October 2014); India (Mumbai, July 2014); India (Chennai, March 2014); Kazakhstan (Astana, September 2014); Myanmar (Yangon, September 2014); Russia (St Petersburg, September 2015); Thailand (Bangkok, June 2015); Turkey (Ankara, October 2014); West Bank and Gaza Strip (Gaza City, July 2015); West Bank and Gaza Strip (Ramallah, July 2015) [12]	Canada (Ottawa, June 2014); Chile (Santiago, July 2014); El Salvador (San Salvador, October 2014); Panama (Panama City, November 2015) [4]
Signed Agreements ³	17	Cote d'Ivoire, Congo, Kenya, Mauritius, Mozambique, Senegal, South Africa, Uganda, Zimbabwe [9]	India, Iran (Islamic Republic of), Turkey [3]	Argentina, Colombia, Guatemala, Mexico, Uruguay [5]

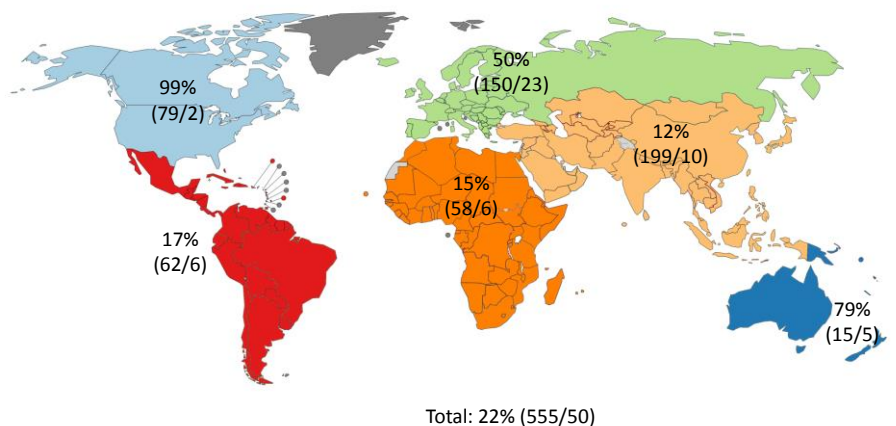
¹ Classified into continents according to IARC Hub involvement; activities in Oceania will commence in 2016

² Only initial visits to countries are listed

³ Includes agreements signed by the African Cancer Registry Network to provide an IARC Regional Hub for Sub-Saharan Africa

Incidence data

% of the population covered by cancer registration around 2012
(*number of registries/number of national population-based registries)



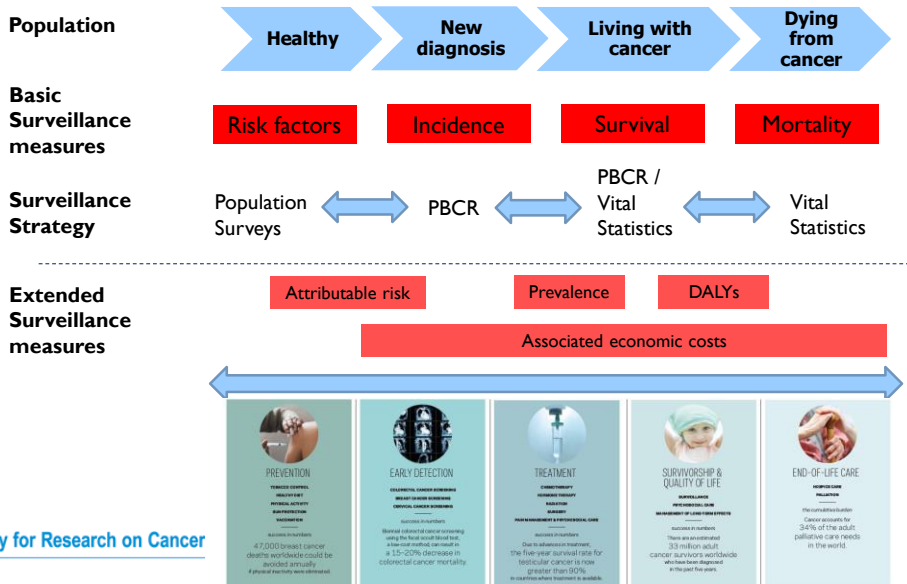
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Map production: IARC
World Health Organization

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* Member Registries of the International Association of Cancer Registries which submitted data to IARC.

Measures & strategies for cancer surveillance



Slide: Dr Marion Pineros, adapted from Wingo et al. Cancer Causes Control 2005; 16(2):151-70 / Cancer Atlas 2nd Edition.



Cancer Epidemiology Special Issue: Cancer in Small States (2017)

7 April 2016

Dear Colleagues,

Small states (and dependencies) defined here arbitrarily as those with populations fewer than 1.6 million people) face a number of unique challenges in cancer control. These challenges include economies of scale with regard to training, care, distance, complex dependencies with faraway 'mother' countries, differing levels of development, and not least, climate change.

About 29 million people live in small states, a population the size of Nepal or Australia. While these comprise 0.4% of the total world population, there are 105 such small states out of 258 countries and dependencies (40% of total).

The literature on this important topic is disproportionately sparse. For this reason, *Cancer Epidemiology* (11: 2711) has decided to compile a special issue on *Cancer in small states* with an intended publication date of mid-2017. By doing so, we hope to promote evidence-based policies on cancer control in these places.

We would welcome descriptions of the current situation, and solution-based contributions from colleagues who are working in small states. Topics can range from cancer control policies, experiences with treatment, surgery, radiation therapy and chemotherapy provision, transport issues, health economics, cancer registration and mortality statistics and epidemiological and clinical insights.

The format is flexible, as per the *Cancer Epidemiology* guidelines. We will consider, for example, opinion pieces, letters, reviews and original research reports.

Contributors will be assisted by a dedicated editorial team and via our peer review process.

We would appreciate any enquiries or expressions of interest by mid-May 2016 with view to paper submission by November 2016. Please send enquiries to CancerEpidemiology@elsevier.com.

A Prof Freddy Sitas, Assistant Editor, and Sarah Jenkins, Executive Publisher, *Cancer Epidemiology*, Elsevier

Professor Michael Barton, Professor of Radiation Oncology at UNSW, and Research Director of the Collaboration for Cancer Outcomes Research and Evaluation (CCORE)

Dr John Flanagan, NCD Coordinator, US-National Cancer Institute

Dr Freddie Bray, Section Head, Cancer Surveillance Section, International Agency for Research on Cancer

Dr Sunia Foliaki, Centre for Public Health Research, Massey University, New Zealand

Dr Ashley Cliff, Commissioning Editor, *Cancer Epidemiology*

Elsevier Limited, The Boulevard, Langford Lane, Kidlington, Oxford OX5 1GB, UK
Tel: +44 (0) 1865 843000 / Fax: +44 (0) 1865 843009 / www.elsevier.com

Special Issue on Cancer in Small Nations:

- Global health development challenges
- Cancer surveillance and vital registration: networking and gaps
- Cancer control policies: from prevention to palliative care

Evolving Cancer Registration in Oceania: Building Capacity to Inform Cancer Control An IARC Regional Workshop

- To provide participants with the opportunity to gain insight and contribute ideas on current developments in cancer registration within Oceania.

Evolving Cancer Registration in Oceania: Building Capacity to Inform Cancer Control

Wednesday 13 April 2016, Brisbane Australia

PROGRAM

Purpose: To provide participants with the opportunity to gain insight and contribute ideas on current developments in cancer registration within Oceania.

Format: Plenary presentations followed by interactive small group sessions.

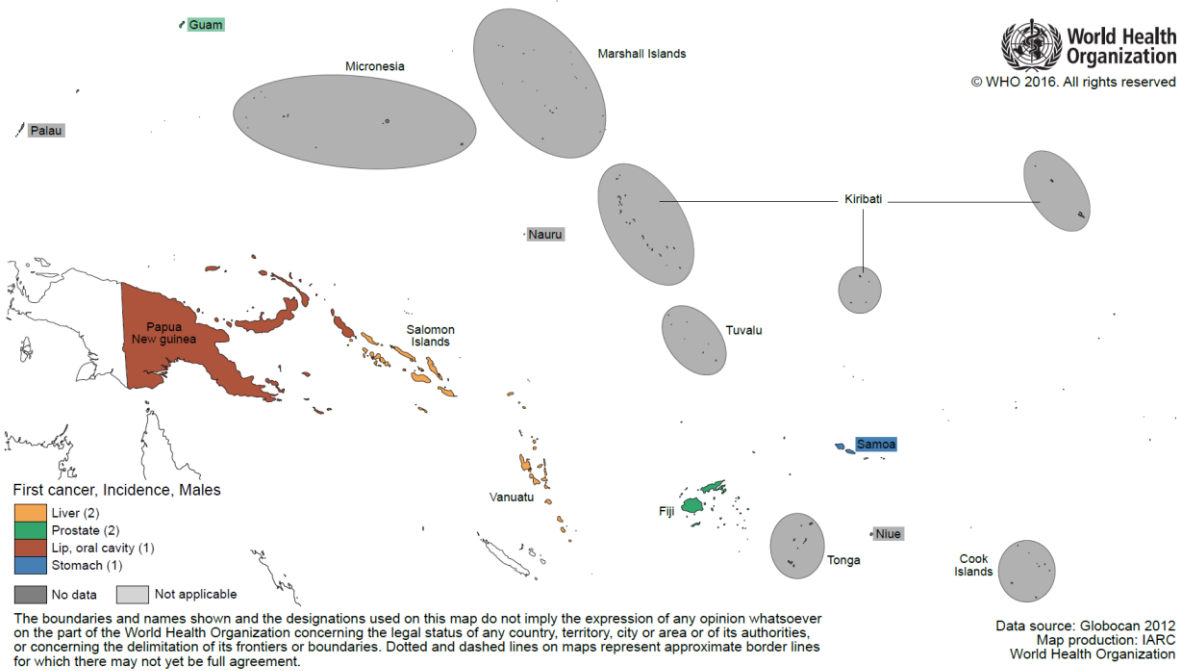
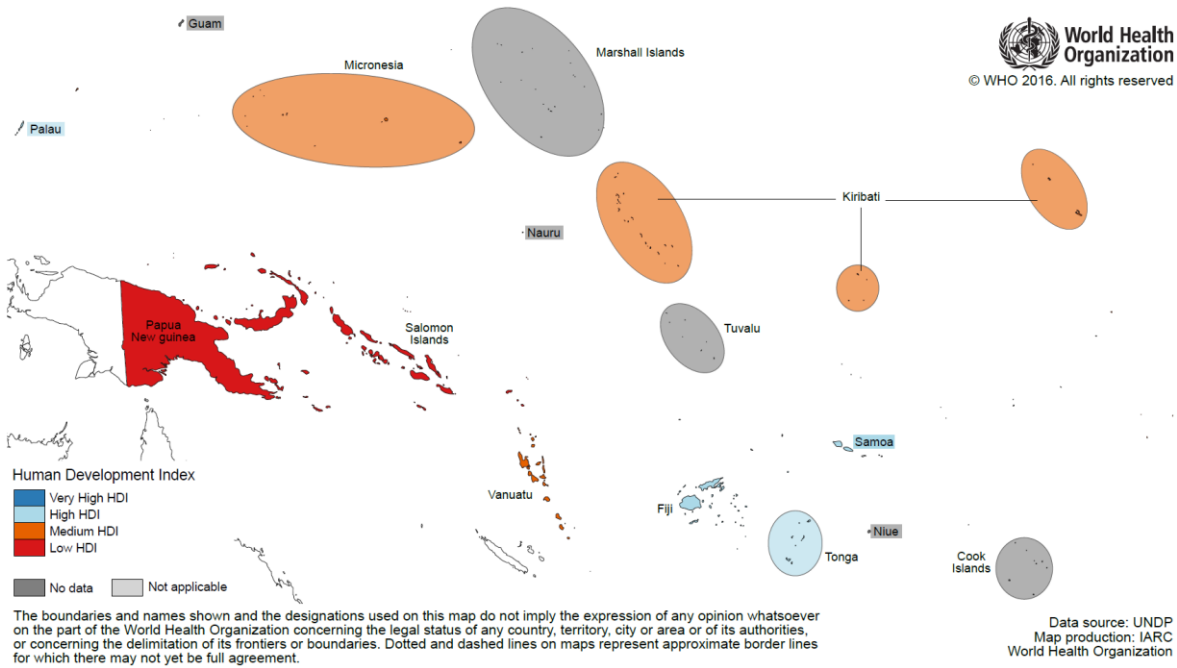
Evolving Cancer Registration in Oceania: Building Capacity to Inform Cancer Control	
08:30	Opening Remarks: Jeff Dunn
08:40	I: The Cancer Burden
08:55	Cancer in the Pacific Islands: Joanne Aitken
09:10	II: Cancer Surveillance in the Pacific Islands
09:25	Progress and challenges for pathology services in the Pacific region: Rajhwa Sharma
09:55	Reports from selected countries
10:15	Question and discussion
10:45	Morning tea
11:00	III: Planning for the future
11:15	Cancer data for Cancer Action: The Global Initiative for Cancer Registration: Les Mery
11:30	IARC Regional Hub for the Pacific Islands: Plans and priorities: David Roder and Sunia Foliaki
11:45	Explanation of small group sessions: Les Mery
12:00	Breakout sessions: Gathering perspectives
12:15	Lunch
12:30	III: Planning for the future Cont'd
13:00	Group reports and discussion
13:15	IV: Regional Activities
13:30	Role of the Australasian Association of Cancer Registries in the Pacific Island Hub: Helen Farrugia
13:45	International Association of Cancer Registries: strategic areas and engagement: Roberto Zanetti
14:00	Breakout session: Developing a regional network for Oceania
14:15	Afternoon tea
14:30	Group reports and discussion
14:45	The way forward: Next steps: Chris Wild
15:00	Adjourn
15:15	Welcome Reception - Plaza Foyer

For details on registration and associated meetings go to www.aaccr.org.au

Proudly hosted by:



FINAL VERSION



Summary

- Increasing but inequitable cancer burden
- The importance of cancer as a health problem underlines the need for systematic cancer control programmes maximising scarce resources.
- Population-based cancer registry data are essential components in planning and monitoring of such programmes.
- Very limited data to inform cancer control
 - but a solution is available
- The GICR and the implementation of Regional Hubs aims to extend and improve cancer registration worldwide .

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