Global Initiative for Cancer Registry Development in Low and Middle-Income Countries (GICR)

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Lyon, France

AIRTUM, Bolzano, 20 March 2013
“Population-based cancer registries play a central role in cancer control programmes because they provide the means to **plan, monitor and evaluate** the impact of specific interventions in targeted populations”.

- Which cancers are common
- Trends over time
- Future burden
- Effects of treatment
- Impact of interventions
Estimated global burden of cancer

Estimated annual number of new cancer cases 2008 and predicted 2030, by World Bank income groups

LMIC > 50% of current burden and 60-70% of burden in 2030 but least equipped to cope with this situation – also re PBCR
GLOBOCAN 2008
Incidence – methods of estimation

1: National incidence data
2: Local incidence data and national mortality data
3: Local incidence data. No mortality data
4: Frequency data
5: No data
CI5 I - IX

Countries
Populations
Registries

22, 34, 31
60, 300, 225

1966
2007
## CI5 IX breakdown

<table>
<thead>
<tr>
<th>Region</th>
<th>% Pop: 11.6</th>
<th>Registries: 225</th>
<th>Countries: 60</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>1.1</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>C&amp;S America</td>
<td>5.5</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>N America</td>
<td>83</td>
<td>54</td>
<td>2</td>
</tr>
<tr>
<td>Asia</td>
<td>4</td>
<td>44</td>
<td>15</td>
</tr>
<tr>
<td>Europe</td>
<td>32.5</td>
<td>100</td>
<td>29</td>
</tr>
<tr>
<td>Oceania</td>
<td>80.5</td>
<td>11</td>
<td>2</td>
</tr>
</tbody>
</table>
Disparities in presence of high quality PBCR:
% population covered by cancer registries Cl5, IX

(number of registries/number of countries providing data)
## Inclusion of African cancer registries in CI5 I-IX

<table>
<thead>
<tr>
<th>Country</th>
<th>Registry</th>
<th>CI5 volume</th>
</tr>
</thead>
<tbody>
<tr>
<td>Algeria</td>
<td>Algiers</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Sétif</td>
<td>x x x</td>
</tr>
<tr>
<td>Egypt</td>
<td>Gharbiah</td>
<td>x</td>
</tr>
<tr>
<td>Mali</td>
<td>Bamako</td>
<td>x x x</td>
</tr>
<tr>
<td>Mozambique</td>
<td>Lourenço Marques</td>
<td>x</td>
</tr>
<tr>
<td>Nigeria</td>
<td>Ibadan</td>
<td>x x x</td>
</tr>
<tr>
<td>Senegal</td>
<td>Dakar</td>
<td>x</td>
</tr>
<tr>
<td>South Africa</td>
<td>Jo'burg Bantu</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Natal African</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Natal Indian</td>
<td></td>
</tr>
<tr>
<td>The Gambia</td>
<td>National CR</td>
<td>x x x</td>
</tr>
<tr>
<td>Tunisia</td>
<td>Centre (Sousse)</td>
<td></td>
</tr>
<tr>
<td>Uganda</td>
<td>Kyadondo (Kampala)</td>
<td>x x x x</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>Bulawayo African</td>
<td>x x x</td>
</tr>
<tr>
<td></td>
<td>Harare African</td>
<td>x x x</td>
</tr>
<tr>
<td></td>
<td>Harare European</td>
<td>x</td>
</tr>
</tbody>
</table>
Cancer registration in LMIC: challenges

• **Establishment and sustainability of registries**
  lack of: basic health services; trained personnel; census data; data processing facilities; cooperation from medical personnel; political support, funding…

• **Quality of registries**
  no pathological diagnosis, no mortality statistics; difficulty linking different datasets; lack of follow-up; lack of trained personnel…

• **Utilization of data generated by registries**
  capacity to study cancer burden, time trends; to evaluate screening programmes, to measure survival, to identify risk factors…
The Global Initiative for Cancer Registry Development in LMIC (GICR)

- Multi-partner approach led by IARC, launched Nov. 2011
- Aim: to develop capacity in LMICs to produce reliable, high-quality information on the burden of cancer – a key response to the UN Political Declaration on NCD (Sept. 2011) and WHA65 resolution on global monitoring framework (May 2012)
- Implementation of GICR through a network of Regional hubs
- Training, advocacy and outreach program
- Estimated minimum funding requirements: 5mio $ over 5 years
- [http://gicr.iarc.fr](http://gicr.iarc.fr)
GICR - a stepwise approach to develop PBCR

Less than one in five of all LMIC have population-based cancer registries of CI5 quality. The need for these countries is to ensure this quality status is maintained.

In about 25% of LMIC there are hospital-based cancer registry systems in place. Around 40 countries in LMIC have population-based cancer registry systems at varying quality levels. The common need is to strengthen and transform these registries.

Close to 25% of LMIC have no reasonable source of cancer data available either nationally or regionally.
Implementing GICR through IARC Regional Hubs for cancer registration

<table>
<thead>
<tr>
<th>Technical support</th>
<th>Training</th>
<th>Research</th>
<th>Advocacy &amp; Networking</th>
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</table>

PI: Dr S Eser
PI: Dr R Dikshit
PI: Dr M Parkin

2013
Example of Hub activities - Mumbai

**Training**
- Annual one-week course within region: Mumbai, 2/2012; Jakarta, 5/2013
- Support to national course (Thailand)
- Individual training at Hub
- CanReg train-the-trainers

**Support**
- 3-year Collaborative Research Agreements (CRAs) with Cancer Registries in Indonesia, Mongolia and Sri Lanka
- Site visits

**Research**
- Cancer in Maharashtra & Goa 2007-9
- Cancer in Asia 2003-7

**Advocacy & Networking**
- Outreach to national authorities; Alumni
GICR- the first year

- **Technical support** to cancer registries: establishment of 3 regional hubs; expert visits; CanReg clinics; development of staging tool for CanReg with NICR....
- **Training** regional (Asia, Africa, Latin America), language-specific and *ad hoc* courses; CanReg webinars....
- **Research** through Collaborative Research Agreements, methodology and regional publications...
- **Networking, Outreach and Advocacy** to explain the importance and cost-effectiveness of cancer registration; to empower the cancer registry community to be advocates; surveys to prioritize work

- **GICR website** in English, French, Spanish [http://gicr.iarc.fr](http://gicr.iarc.fr)
- **Fundraising**: ~1mio USD
On Acronyms and Synergies

Organizations endorsing GICR:

- American Cancer Society
- Aortic OAREC
- Barbados National Registry
- CDC
- DUTCH CANCER SOCIETY
- ECL
- European Network of Cancer Registries
- Fondo Anglesio Moroni
- International Association of Cancer Registries
- IAEA
- INCTR
- NaAACC
- National CANCER INSTITUTE
- Pan American Health Organization
- RINC
- World Health Organization

International Agency for Research on Cancer
On Acronyms and Synergies/2

- **Target countries / calendar of site visits**
- **Training** fellowships/grants to support language-specific and *ad hoc* courses
- **Roster** of experts
- **Development/dissemination** of relevant information
- **Visibility**: reciprocal links on websites
- **Outreach and Advocacy** to explain the importance and cost-effectiveness of cancer registration
- Capitalize on **common collaboration** within umbrella organizations
- **Twinning**
- **Internships**
- **Collaborative research**
- **Joint calls for proposals**
- **Funding /Fundraising** including door-opening
Join GICR!


- As a cancer registry
- As an association (e.g. AIRTUM)
- As a cancer registry professional (active or retired)

- Share your expertise, mentor or host a cancer registrar, twin with a cancer registry, engage in collaborative research, help spread the word…