Data on cancer from Africa

The African Cancer Registry Network

Dr D Maxwell Parkin
Oxford, UK
No Conflicts of Interest
Estimates of INCIDENCE, MORTALITY and PREVALENCE of 27 types of cancer

http://globocan.iarc.fr
Africa

**Incidence**
- Breast: 34.1%
- Liver: 15.0%
- Prostate: 15.2%
- Cervix uteri: 25.3%
- Colorectum: 10.5%
- Other: 46.3%
- Total: 847,000 new cases

**Mortality**
- Breast: 25.1%
- Cervix uteri: 23.9%
- Liver: 22.3%
- Prostate: 17.0%
- Colorectum: 11.7%
- Other: 42.5%
- Total: 591,000 deaths

**Prevalence (5 years)**
- Breast: 43.9%
- Cervix uteri: 25.6%
- Prostate: 15.6%
- Colorectum: 6.3%
- Kaposi sarcoma: 8.7%
- Other: 55.8%
- Total: 1.8 million persons

Where does all this information come from?
CANCER INCIDENCE

54 countries (>100,000 population)

Estimated for 20

DATA FROM CANCER REGISTRIES – 34
Mortality

METHODS

Mortality statistics – 4 countries

Estimated from national incidence using survival data
HISTORY OF AFRICAN CANCER DATA

1900 –1950 Case reports

1950’s Case series (hospitals, pathology)
Sir Albert Cook established Mengo Hospital in Kampala (Uganda) in 1897.

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HISTORY OF AFRICAN CANCER DATA

1900 –1950  Case reports

1950’s  Case series (hospitals, pathology)

1960’s  Comparative studies- frequencies in different hospitals/laboratories
A "TUMOUR SAFARI" IN EAST AND CENTRAL AFRICA
DENIS BURKITT

Map of East and Central Africa. All areas above 3000 ft. are shaded. The crosses indicate areas from which tumour patients have been observed.

PROPORTIONAL OCCURRENCE OF BURKITT'S LYMPHOMA
(By hospital; both sexes at all ages)

Type of cancer:
- Burkitt's lymphoma
- Histologically confirmed cases
- Clinically diagnosed cases
- Stomach; liver; scar epithelioma; Kaposi's sarcoma
HISTORY OF AFRICAN CANCER DATA

The first true cancer registries:
Cancer Incidence in Five Continents
Volumes I-III
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<th>Volume(s)</th>
<th>Dates</th>
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<td>Johannesburg (Higginson &amp; Oettle)</td>
<td>Volume I</td>
<td>1953-55</td>
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<tr>
<td>Capetown (Muir Grieve)</td>
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<td>1956-59</td>
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<td>Durban (Natal) (Schonland and Bradshaw)</td>
<td>Volume II</td>
<td>1964-66</td>
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<td>Kampala (Davis, Templeton)</td>
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<td>Lourenco Marques (Maputo) (Prates)</td>
<td>Volume III</td>
<td>1956-60</td>
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<td>Ibadan (Edington)</td>
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<td>1960-62</td>
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<td>Bulawayo (Skinner)</td>
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<td>1963-67</td>
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1980’s Renaissance

1986: Cancer Registry of Mali (Bamako)

1989 Cancer Registry of Setif (Algeria)

The Gambia (1986)
Gambia Hepatitis Intervention Study (GHIS)
( IARC, MRC, Gambia MOH)
Incidence data

% population coverage (Ci5 volume X)

- 2%
- 8%
- 38.2%
- 78%
- 6%
- 95%
- 42%
- Total ~ 14%

78%
A global strategy to improve the ability to collect, analyse and communicate cancer data
AFCRN is a consortium of population-based cancer registries that provides the activities of a Regional Hub role with respect to cancer registry support in sub Saharan Africa.

www.afcrn.org
AFCRN Membership Criteria

- Membership is by invitation following a consultant visit of evaluation
- Two existing members may propose new members for evaluation
- Registries in the countries of Sub-Saharan Africa (the WHO-AFRO region, minus Algeria) are eligible for membership

- The registry must be POPULATION BASED, and achieving at least 70% coverage of the target population*

- Members must accept participation in joint AFCRN projects:
  - as approved at the AFCRN Annual Meeting
  - and approved by the AFCRN Research Committee

- Members must adhere to the policy (as agreed at the AFCRN Annual Meeting) on International Collaborative Research
- Members must maintain an up to date Web Page on the Network website
- Member registries should contribute data to the African Cancer Registry Database
- Representatives from member registries should not be absent at two consecutive annual meetings

*Probationary period of 3 years permitted with coverage 50-70%.
AFCRN membership on Feb 1st 2017

List of countries:
Benin
Botswana
Congo (Republic of)
Cote d'Ivoire
Ethiopia
Gambia
Ghana
Guinea
Kenya
Malawi
Mali
Mauritius
Mozambique
Namibia
Niger
Nigeria
Reunion
Seychelles
South Africa
Uganda
Zambia
Zimbabwe

31 registries
22 countries
The role of a regional hub is in:

- providing technical and scientific support to countries;
- delivering tailored training in population-based cancer registration and use of data;
- advocating the cause of cancer registration in the region and facilitating setting up associations and networks of cancer registries; and
- coordinating international research projects and disseminating findings.
Regional Hub function 1:
Providing technical and scientific support to countries

- Memoranda of Understanding

Provide funding to resolve identified problems
- equipment, temporary staff, travel...

- Technical assistance by AFCRN Research Fellows

- Installation and training in CanReg
Technical consultancies in 2016

- Brazzaville (Congo)
- Mwanza & Kilimanjaro (Tanzania)
- Beira & Maputo (Mozambique)
- Zambia
Region Hub function 2:
Training in Population-based Cancer Registration, CanReg and Use of Data

Basic training for cancer registration team in Cape Verde
March 2016

Basic course, Accra, Ghana June 2016

Advanced course on CanReg, Kampala, Uganda, October 2016

Second IAEA/WHO/AFCRN Workshop on Cancer Registration and Cancer Control, Accra, Dec 2016
Region Hub function 3: Advocating the cause of cancer registration in the region and facilitating setting up associations and networks of cancer registries

In last 4 years, AFCRN consultants had held talks with representatives from Ministry of Health and/or NCD departments of countries e.g. Rwanda, Senegal, Burkina Faso, Mauritania, Botswana, Liberia, Benin, Togo, Cameroon, Zambia, Nigeria, and Seychelles.

As well as attending world class conferences and organising annual meeting.
PUBLICATIONS by AFCRN, member registries and/or through collaboration

Examples of publications:

- **Cancer Incidence in Harare, Zimbabwe:**
  - Authors: Ima-Obong A. Ekanem, Donald M. Parkin

- **Cancer Incidence in rural Eastern Cape Province, South Africa:**
  - Title: Five years cancer incidence in rural Eastern Cape Province, South Africa, 1998–2012
  - Authors: Sihlobo Laneke, Baddhoo Debbie

- **Incidence of cancer in Nairobi, Kenya:**
  - Authors: Anne Koa, Nathan Chirinos, Victor Rono, Geoffrey Matama, Max Parkin

These publications are variously from the International Journal of Cancer, Elsevier, and other reputable journals.
TECHNICAL PUBLICATIONS

CANCER of CHILDHOOD in AFRICA

I. INCIDENCE

Catherine Kituwa, Freddie Bray, Jacques Ferlay, Byung Hui, O. Manne-Warimbe
The African Cancer Registry Network (AFCRN) was formally inaugurated on 1st March, 2012. It is supported via the Cancer Registry Programme of the International Network for Cancer Treatment and Research (INCTR). AFCRN has succeeded and expanded the activities of the East African Cancer Registry Network (EARN), which was established in January 2011, thanks to the support of the Doris Duke Charitable Foundation (USA). The aim of the project was to improve the effectiveness of cancer surveillance in five east African countries by providing expert evaluation of current problems and technical support to remedy identified barriers, with long-term goals of strengthening health systems and creating research platforms for the identification of problems, priorities, and targets for intervention. The success of the EARN project has attracted further support, as a grant from the pharmaceutical company GlaxoSmithKline (GSK) - Oncology division. This has permitted expansion of activities to the whole of sub-Saharan Africa. These financial contributions to the work of cancer registration in Africa are a recognition of the increasing burden of non-communicable diseases, and especially cancer, in the continent, and the need for adequate surveillance as a fundamental part of any rational programme for cancer control. In
Annual Review Meeting of AFCRN, Kumasi, December 2016
Problems of cancer registration in Africa

1. Structural
   1. Lack of institutional framework
   2. No legal provision for cancer registration

2. Technical
   1. Some patients may never attend medical facilities (never diagnosed)
   2. Difficulties in case finding and abstracting
   3. “Place of residence” is difficult to define, and to collect
   4. Regular population estimates not available, or in insufficient detail.
   5. Follow-up studies (survival) very difficult
   6. Recruiting, training and retaining good quality registry staff is difficult

3. Financial
   Local funding is difficult to obtain and maintain
HOW MUCH DOES IT COST?

(left): Survey of 17 AFCRN member registries’ budgets by number of cases registered (right)(excluding Gambia & Kumasi).

About $9 per case
FUTURE DIRECTIONS FOR AFRICA

- Increase the registry network
- Improve quality (completeness & validity)
- Expand dataset
  - Stage (?Essential TNM)
  - Outcome (survival)
  - Treatment
- Automation – linkage of files
  - Speed and simplify data collection
  - Expand range of activities
    - Surveillance of disease
    - Research
African Cancer Registry Network (AFCRN)

www.afcrn.org

Our supporters (with thanks for their contributions)

Other significant partners
Network of Population-Based Cancer Registries in Sub Saharan Africa
African Cancer Registry Network

KNOWLEDGE is key to NATIONAL CANCER CONTROL PLANNING in SUB SAHARAN AFRICA

In the fight against CANCER, knowledge of the problem to be confronted is just as important as knowing the solutions. Cancer has never been rare in Africa. As populations age and become urbanised, cancer is emerging as a major challenge to health and wellbeing.

What's my chance of getting cancer before I'm 70?

<table>
<thead>
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<th>Percent of deaths due to Cancer</th>
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<td>Year</td>
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MUST KNOW:
Patterns of cancer
Change of burden
Affected population
Available treatments
Patients' choices
Treatment outcomes

TO PLAN:
Prevention
Early detection
Treatment
Palliative care
Budgeting; marketing
Health education

POPULATION-BASED CANCER REGISTRIES (PBCR) is

WHO WE ARE
Network of Population-Based Cancer Registries, International Organisations and Research Institutes.

We aim to cover all PBCRs in Sub Saharan Africa. So far, 30 PBCR in 22 countries are members:
Bénin; Botswana; Côte d’Ivoire; Congo, Rep.; Ethiopia; Gambia; Ghana; Guinea; Kenya (3); Malawi; Mali; Mauritius; Mozambique; Namibia; Niger; Nigeria (4); Reunion; Seychelles; South Africa (3); Uganda (2); Zambia; Zimbabwe (2).

Significant Partners: University of Halle, South African Medical Research Council, Union for International Cancer Control, American Cancer Society, etc.

WHO BENEFITS
* Hospital staff in Africa: 100+ cancer registrars trained; 9 training instructors;
* Cancer registries: general funding support; research grants; fellowship;
* African researchers: 10+ international joint publications;
* Policy makers (local government and international organisations e.g. WHO): by improving data quality and making information available;
* Countries in SSA: more effective and efficient cancer control planning and evaluation possible.

Through the support of AFCRN we have provided essential information to researchers, the Ministry of Health and other stakeholders for use in prioritizing cancer prevention and control programmes. In Kenya, cancer registration is now well recognized as the best surveillance method that can provide accurate data on cancer incidence and mortality.
As a leader in cancer registration I am often consulted by Ministers of Health to help develop registries in other regions of Kenya.
AFCRN is like a family that share common goals, values and aspirations. We learn from each other... the Network gives us guidance and courage to do much more.

-- Anne Korir
Director, Kenya National Cancer Registry

WHAT WE DO
We aim to provide mentoring and advice, staff training, to foster research on cancer cause and prevention, and to advocate for policies for cancer control. The expertise for these tasks is provided by the AFCRN members, guided by a coordinating centre, which works closely with the International Agency for Research on Cancer (IARC) - the cancer agency of the World Health Organisation (WHO).

Join the mission:
$100,000 Mission support
Acknowledged in all activities; invites to annual meeting.

Training:
$40,000 international training course
$20,000 regional training course
Acknowledged on all course materials.

Registry development:
$3,000-5,000 per registry sponsorship
$5,000 individual fellowship
Acknowledged on all publications.

Research:
£40,000 per annual - Oxford DPhil student
£20,000 per research project
Acknowledged on all publications.

admin@afcnn.org

We have many more ongoing projects concerning different areas, countries and studies. For more information please email.

AFCRN relies entirely on donations to support its work. Donations may be for specific activities, and/or for limited periods. The AFCRN is funded through The INCTR Challenge Fund (registered charity in England and Wales. Charity number: 1079181). Its account is audited annually. UK company may receive tax relief by making a donation to a registered charity.

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Thank you