AFCRN Progress Report 31st December 2013

DEVELOPMENT OF THE NETWORK
2013 is the second year of the work of the African Cancer Registry Network (AFCRN). AFCRN remains in official partnership with the International Agency for Research on Cancer (IARC); as part of the “Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries”, the Network acts as a consortium to provide a “Regional Hub” services for cancer registries in Sub Saharan Africa (SSA).

The Network is also financially supported by the UK registered charity The Challenge Fund (charity number 1079181) which receives restricted funds to support cancer registries in Africa from GlaxoSmithKline Oncology (GSK), the Doris Duke Charitable Foundation (DDCF) and the American Cancer Society (ACS).

The secretariat of AFCRN is based in Oxford, UK (address above) with Dr Max Parkin (mparkin@afcrn.org) as coordinator and Ms Biying Liu (bliu@afcrn.org) as administrator. A research assistant (Dr Louise Ekobena-Ekobo) was appointed on 1st September. Activities in Africa are assisted by a group of skilled consultants.

ANNUAL REVIEW MEETING 2103
39 participants, directors and leaders of member registries as well as significant individuals, attended the 2 days Annual Review Meeting (ARM) of the Network from 29 to 30th January in Mombasa, Kenya. This was followed by a 3 day scientific workshop on ‘Hematopathology in Africa’ and a one and half day meeting on ‘HIV-associated malignancies in equatorial Africa’ organised by INCTR in association with WHO. The ARM provided the opportunity for members to present their on-going work, and to plan future joint activities in training, advocacy and research in 2013/14. The contribution of the AFCRN to the meeting of AORTIC (November 2013) and to other major conferences was agreed. The AFCRN statutes and rules governing collaborative research were reviewed and amended as agreed by the membership.

ADVISORY GROUP
The Advisory group of AFCRN comprises representatives of WHO (AFRO), IARC, UICC and IACR. The meeting was convened at the same time as the Annual Review Meeting (31st January 2013). Work progress was reviewed, suggestions were made for future activities and external collaborations, as well as identifying additional sources of funding for the Network.

MEMBERSHIP
The Membership continues to expand in 2013. To date, the Network is supporting and/or assisting the development of 25 cancer registries in Sub Sahara Africa, including English, French and Portuguese speaking countries. A list of current Members is shown in Appendix 1.

TRAINING in 2013
Intermediate level training course in French
13 experienced registrars from francophone countries were trained at the Kigali Cancer Registry in Rwanda, from 8th-19th July. It was a two weeks course, and included revision of basic procedures, some more advanced concepts (staging of cancers from clinical records, follow up and survival, basic data analysis), and CANREG-5 training.

<table>
<thead>
<tr>
<th>Nom et Prenom</th>
<th>Provenance</th>
<th>Profession</th>
<th>E-mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Kababa Ibrahim s</td>
<td>Guinée Conakry</td>
<td>Medecin</td>
<td><a href="mailto:kabbaibrahim@hotmail.com">kabbaibrahim@hotmail.com</a></td>
</tr>
<tr>
<td>Mohamadou Hamidou Victor</td>
<td>Niger</td>
<td>Laborantin</td>
<td><a href="mailto:Hamidou3fr@yahoo.fr">Hamidou3fr@yahoo.fr</a></td>
</tr>
<tr>
<td>Ibara Gerard</td>
<td>Congo</td>
<td>Epidemiologiste</td>
<td><a href="mailto:pasteurgibara@gmail.com">pasteurgibara@gmail.com</a></td>
</tr>
<tr>
<td>Dr Rina Sewpaul-Sungkur</td>
<td>Ile Maurice</td>
<td>Pathologist</td>
<td><a href="mailto:rsewpaul@hotmail.com">rsewpaul@hotmail.com</a></td>
</tr>
<tr>
<td>Uwimbabazi Mathilde</td>
<td>Rwanda</td>
<td>Nurse</td>
<td><a href="mailto:mathilde.uwimbabazi@yahoo.fr">mathilde.uwimbabazi@yahoo.fr</a></td>
</tr>
</tbody>
</table>
CanReg 5 Training
Technical support and enhanced training was requested by member registries in Nairobi, Tanzania, Addis Ababa and Brazzaville. Ms Gladys Chebet (Eldoret Cancer Registry, Kenya), supported by AFCRN and trained in IARC, paid an consultant visit to the Nairobi Cancer Registry to help and answer questions and solve problems of the local staff and to give a 2 days training on CanReg 5 to the Nairobi team. Dr Parkin is assessing the needs and support for the other three.

Translating teaching materials into French In order to provide tailored training to French speaking cancer registry staff, some of the material used in the AFCRN courses has been translated by Dr Sabine Perrier-Bonnet (until end of July) and Ms Elisabeth Dupont, our French speaking consultants.

AFCRN Fellowship - Professional Training Profession Henry Wabinga from the Kampala CR and Mr Eric Chokunonga from the Zimbabwe National CR spent 4 week fellowship periods in Oxford (from 9th Sep – 4th Oct), working on the publication of results from their registries.

ICD-O-3 An order for 30 copies of English version and 5 copies of French version has been made to WHO via the IACR secretariat in Lyon. The publication will be used for future courses. The Network is covering all the costs. Nothing has been received.

TNM French 7th Edition With help from UICC, 20 copies were purchased and used at the Kigali course. The cost was covered by the Network.

ADVOCACY
WAHO. Mr Eric Chokunonga was invited to a meeting in Accra, Ghana, 27-28th June, sponsored by the West African Health Organisation, where he presented the work (results, consultancy view on individual registry) done by the Network.

World Cancer Leaders Summit (Cape Town, Nov 18-19th). Dr Parkin, Dr Korir (Nairobi CR, Kenya) and Prof Gombe (Brazzaville CR, Congo) will represented the AFCRN at the UICC partner events complementing the World Cancer Leaders Summit, to draw attention to the work of cancer registries in Africa, and to urge donor support for their work.

AFCRN Workshop. (Durban 20th November) The Workshop was chaired by Prof Eva Kantelehardt, the aim was to discuss the new project AFROCaNN, which has been approved for preliminary funding, and, if the final application is successful, will involve collaboration with AFRCN. Participants also shared individual experience with the on-going studies of breast cancer (data collection, case follow up and/or any other difficulties encountered).

AORTIC Conference: Cancer in Africa: Bridging Science and Humanity. Several members of AFCRN attended the conference of AORTIC in Durban, South Africa, 21st-24th November 2013. A session presenting the work of AFCRN was held on 22nd November:

**SESSION African Cancer Registry Network (Friday 22 November 1430-1730)**

- **Chairs:** Donald Maxwell Parkin and Charles Gombe (Congo)
- **History and development of AFCRN**
- **Estimates of cancer incidence and mortality in sub Saharan Africa in 2012**
  - Anne Finesse (Seychelles)
- **The costs of cancer registration in sub Saharan Africa**
  - Maxwell Parkin (UK)
- **The cancer profile in West Africa**
  - Robai Gakunga (Kenya)
  - Elim Jedy-Agba (Nigeria)
Childhood Cancer in Africa
Cristina Stefan (RSA)

Time trends in cancer incidence in Africa
Eric Chokunonga (Zimbabwe)

Breast cancer incidence by size and stage of tumour
Ahmedin Jemal (ACS - USA)

Cervix cancer: incidence and survival
Anne Korir (Kenya)

Oesophagus cancer in East Africa: incidence and survival
Katherine van Loon (USA)

Dr Parkin co-chaired, and also presented the work of AFCRN during a session organised by IARC (21st November) entitled “The case for cancer registries in Africa”.

35th IACR Conference 2013. Ms Anne Korir, as the IACR representative of Africa, attended the 35th IACR Conference 22-24th October in Buenos Aires, Argentina and presented the activities of the Network.

CONSULTANCIES
Visits by Dr Max Parkin
On 8-9th and 10-11th April, a visit was made to review the feasibility of, and requirements for, a population based cancer registry in Togo and Benin respectively. Reports on both registries were prepared. A copy of the report for Benin has also been sent to IAEA. Subsequently, the newly-appointed cancer registrar from Benin attended for training in Kigali (see above).

On 21-26th April Max, accompanied by Dr Elisabete Weiderpass Vainio (Cancer Registry of Norway), visited Mozambique, to advise the Head of the NCD programme at the Ministry of Health (Dra Carla Matos) on establishing a cancer registry in the capital Maputo. They also visited the cancer registry in the second city (Beira). Reports and recommendations have been sent to Dr Josefo Ferro in Beira CR and to Dr Caria Matos in Maputo. A membership invitation was sent to and accepted by Dr Josefo Ferro, and plans are underway to convert the registry database to CanReg-5 and train the cancer registrar in its use.

On 17th-21st July Max, accompanied by Prof Henry Wabinga and Ms Sarah Nambooze from the Kampala Cancer Registry, visited the cancer registry in Mwanza, Tanzania. A report and recommendations have been sent to the local investigators, who had requested support to initiate cancer registration.

On 22nd July Max visited Dr Anne Korir in Nairobi Cancer Registry and discussed on-going research projects and future collaborations between the Network and the Registry. A first draft of a report on registry activities and results for 2004-2008 was prepared.

On 26-30th August Max visited the Botswana National Cancer Registry (BNCR) to advice on cancer registration methodology and to discuss potential collaborations between the Network and the Registry. A Report has been prepared (and also for IAEA). The registry has accepted an invitation to become the 25th member of the Network.

On 14th – 17th October Max, accompanied by Dr Louise Ekobena Ekobo, visited Lubumbashi, Democratic Republic of Congo to discuss the feasibility of establishing a cancer registry. A report has been finalised and shared with key individuals from WHO and UICC. Discussion on how AFCRN may assist the development of the registry is ongoing. In the meantime, a copy of the ICD-0 in French has been sent to the Registry to allow the coding and entry of cases in the pathology department.

Mr Eric Chokonunga visited Addis Ababa Cancer Registry from 5th to 12th April. Activities of the registry were observed and evaluated. Report and recommendations have been prepared.

On 30th October to 1st November Eric, accompanied by Dr Louise Ekobena Ekobo, visited the Kumasi Cancer Registry. The aim of the visit was to assess progress in converting the registry to a fully functional population based registry, following support from AFCRN since 2012. Report and recommendations have been prepared and shared with Dr Baffour Awuah, Director of Kumasi Cancer Registry. Further discussion will be held during the 2nd Annual Meeting in January 2014.
Mr Chokunonga and Dr Ekobena-Ekobo will be meeting with the Ministry of Health and Social welfare (MOHSW) in Monrovia, Liberia, on 4th-8th November. The aim of this visit will be to discuss how AFCRN may help develop a cancer registry in Monrovia. Report and recommendations have been prepared and shared with the Ministry of Health and Social Welfare (MOHSW). An official meeting was held on January 8, 2014 to discuss the Consultative Report. The meeting was presided over by Assistant Minister Nyenswah with other top staff of the NCD Unit of the MOHSW in attendance. The discussion focused mainly on the Recommendations contained in the Report and they were all accepted by the Ministry. It was also agreed that they are to implement the Recommendations in phases beginning with the appointment of a Technical Committee to lead the effort.

Dr Marilys Corbex visited the registry in Yaounde, Cameroon, 10-14 June, to assess its current condition and situation, and progress it had made since Dr Parkin and Dr Perrier-Bonnet’s visits in 2012. Not much improvement been seen. Further discussions and visits to revitalise this registry will take place in the near future.

Memoranda of Understanding (MoU)
The MoU is the mechanism used by INCTR to set up contracts with the member registries of the AFCRN, to provide them with funds to perform agreed tasks. Between March 1st and 1st November 2013, 8 MoUs for the support of registries have been signed. They are with the cancer registries of Abidjan (Cote d’Ivoire), Conakry (Guinée), Blantyre (Malawi), Mauritius, Harare (Zimbabwe), Eastern Cape/PROMEC (RSA), Kampala (Uganda), and Beira (Mozambique).

COLLABORATIONS
1. IARC. The official partnership between AFCRN and IARC continues. AFCRN provides the facilities and features of a “Regional Hub” for sub-Saharan Africa, as part of the Global initiative for Cancer Registration (GICR). The capacity of AFCRN to undertake this work is supported through funds received via a contract (APW - Agreement for Performance of Work). Up to August 31st, this included funds provided by The GAVI Alliance (the “Global Alliance for Vaccines and Immunisation”) to IARC. A new contract for 2013/2014, starting on 1st September, was agreed, incorporating a contribution of $54000 from CDC, and the funds finally received on 27th December. Dr Parkin has been given the status of an IARC “Senior Visiting Scientist” which enables him to negotiate contracts through IARC.

2. American Cancer Society (ACS). A contract was signed with ACS to provide the study facilities for a joint research project STUDY OF BREAST CANCER SIZE & STAGE in AFRICAN CANCER REGISTRIES. The protocol and data collection form were completed, and 10 registries agreed to take part: Abidjan (Cote d’Ivoire), Addis Ababa (Ethiopia), Mauritius, Ibadan (Nigeria), PROMEC (SA), Nairobi (Kenya), Registre de Cancer de Guinée, Zimbabwe NCR, Brazzaville (Congo) and Kumasi (Ghana). By 31st December, the field work had been completed in 6, and is scheduled to finish in all by 31st March 2014. A post-doctoral fellow (Ms Catherine Okello) has assisted with the field work of this study (full time until 7th June, continues as consultant). Data analysis is being undertaken by Joannie Tieulent at ACS (Atlanta).

3. AFCRN Database. As agreed at the ARM in Mombasa, a database comprising a listing of case records (anonymous) from each AFCRN member has been established. Under a Research Agreement with IARC, the latter organisation has agreed to host the database. Access for research studies will be via request to the AFCRN Research Committee. The first project to make use of the database is the Globocan 2012 national estimates of cancer incidence, mortality and prevalence, organised by IARC. Globocan 2012 was officially launched in December 2013, and can be accessed via the website of IARC (http://globocan.iarc.fr/). All members, with the exception of Rwanda, provided data. Responsible person Ms Elisabeth Dupont (until 31st August).

RESEARCH
Joint research projects within the context of AFCRN (ie, involving more than one member) have to be submitted to, and approved by the AFCRN Research Committee. Criteria for collaborative studies have been developed (http://www.afcrn.org/research-collaboration)
1. A study to document the stage at presentation of breast cancer cases in 10 population based registries in sub-Saharan Africa has been agreed with American Cancer Society (see above). The PI with ACS is Dr Ahmedin Jemal. An interim report was be presented at the AORTIC meeting (22 November), and full analysis will be completed in 2014.

2. Ongoing studies of survival from 4 cancers (breast, cervix, oesophagus and prostate) in four centres (Blantyre, Harare, Nairobi and Kampala) were extended to include follow up of the cases registered in 2004-2008 through to the end of 2012. Data collection in Blantyre and Kampala been completed; the contract for the work in Harare terminates on 31 March 2014.

3. New study of survival on childhood cancer has been in place since early 2013. It involves follow up of a sample of the most common childhood cancers (150-300 cases in total), for 5-10 years post-diagnosis. This study was provisionally planned for 4 registries: Harare, Kampala, Nairobi and Mauritius, although the latter (Mauritius) has too few cases for valid statistical analysis). Follow up is underway in Harare, and just starting in Kampala and Nairobi.

4. Data analysis on oesophageal cancer from East Africa, including the results of the survival study, has been completed. The person responsible is Katherine Van Loon (Assistant Clinical Professor, Department of Medicine, University of California, San Francisco), and the results were presented at AORTIC (22nd November).

5. As part of their MoU agreements, several registries are scheduled to produce complete reports of their work, for periods of 1-3 years, in the format of the AFCRN Model, developed in 2012. They are the registries of Nairobi (Kenya), Blantyre (Malawi), Harare (Zimbabwe), Mauritius and Conakry (Guinée). The cancer registry of Seychelles is also preparing a report for 2009-11. The report for Harare (2010-2012) has been completed will be printed in January 2014.

6. A proposal on Expression of Hormone Receptors in West, East and Southern Africa - Breast Cancer Biology in Africa has been approved by the Network’s Research Committee. It is funded by Dr Eva Kantelhardt (Martin Luther-Universität Halle, Germany). Several AFCRN members, including Beira, Calabar, Conakry, Kampala, Kumasi, Mauritius, Niamey & Rwanda, as well as other pathologists, have agreed to take part, and will each receive a small AFCRN contract to cover their expenses.

7. A collaborative research proposal on African Female Reproductive Organ Cancers in the Context of Emerging NCD’s Networking for Evidence: Universal Access to Cancer Care – AFROCaNN has passed the first stage, and been accepted for a final funding application. The role of AFCRN will be discussed at the 2014 ARM (23rd January 2014), and finally clarified at a meeting in Germany in March 2014.

POST-DOCTORAL FELLOWS
The large volume of work, and the analysis of data being generated by the AFCRN membership, demands the help of a full time Research Assistant.

Ms Catherine Okello, an information analyst from the Thames Cancer Registry, UK, has assisted with the updating of the database, and analysing data collected from the Kampala registry (Uganda). Catherine also helped the 10 centres participating in the Breast Cancer Size & Stage study (vide supra) to develop their protocol and data collection forms. Catherine’s formal post-doctoral Fellowship ended on 26th April 2013, but she continues to provide assistance to several ongoing projects.

Dr Louise Ekobena Ekobo, an AFCRN Research Fellow, has joined the Network from 1st September 2013. Louise is working under the direction of Dr Parkin, to provide scientific support to projects within the African Network. Louise has been providing training and support to Dr Stanislas DJIRO Djomo (MSP) from the Registre de Cancer de Guinée since the decease of Mr KABBA Ibrahim.
WEBSITE
Dr Yohannie Mlombe (Malawi) is responsible for providing support to Biying Liu on the maintenance for the website www.afcrn.org. The website is the main forum for publicising the Network’s activities and collaboration guidelines. Providing an introductory page is one of the criteria of becoming a member of the AFCRN.

PUBLICATIONS

1. AFCRN has collaborated with UICC (and IARC) to produce a short, 6-page brochure (“Cancer Registries: why, what and how?”) describing the purposes, uses, and requirements for a population based cancer registry in low and middle income countries. It is aimed primarily at policy makers, for advocacy and information purposes.

2. A publication based on an analysis of cancer in Harare, Zimbabwe, for the period 1991-2010 has been published. (See picture on the right).


3. A publication of the results of the Kampala cancer registry for a 20-year period (1991-2010) has accepted for publication in International Journal of Cancer. A similar publication of that of the Mauritius cancer registry is being planned.

4. A publication on childhood cancer in Harare (Zimbabwe) for the period 1990-2012 is in preparation

5. Dr Parkin has worked with colleagues from IARC, Lyon, and representatives of the International Association of Cancer Registries (IACR) to prepare a Technical Report “Planning and developing population-based cancer registration in low or middle income settings”. This will provide a short guide to the technicalities of cancer registration, especially for new projects, or recently established registries.

FUTURE ACTIVITIES

Future visits planned in the 2013/4 budget period will include Angola and Namibia (scheduled for January), Mali and Sierra Leone.

New CanReg5 installations will be carried out in Guinée and Beira.

2nd Annual Meeting, Advisory Meeting and AFCRN Workshop have been scheduled for the 21st-24th January 2014, to be held in Victoria Falls, Zimbabwe.

Arrangements to expand the network membership will continue. Membership criteria, as agreed at the ARM, are posted on the website (http://www.afcrn.org/membership/membership-criteria), and will be reviewed at the next ARM.
Appendix 1.

List of members:

Botswana
Botswana National Cancer Registry

Congo (Republic of):
Registre des cancers de Brazzaville

Cote d’Ivoire
Registre des Cancer d’Abidjan

Ethiopia:
Addis Ababa Cancer Registry

Gambia:
Gambia Cancer Registry

Ghana:
Kumasi Cancer Registry

Guinee:
Registre de Cancer de Guinee

Kenya:
Eldoret Cancer Registry
Nairobi Cancer Registry

Malawi:
Malawi Cancer Registry

Mauritius:
Mauritius Cancer Registry

Mozambique
Beira Cancer Registry

Niger:
Registre des cancers du Niger

Nigeria:
Abuja Cancer Registry
Calabar Cancer Registry
Ibadan Cancer Registry
Nigerian National System of Cancer Registries (NSCR)

Rwanda:
Rwanda Cancer Registry

Seychelles:
Seychelles National Cancer Registry

South Africa:
PROMEC Cancer Registry (Eastern Cape)
South African Children’s Cancer Group (SACCSG) Tumour Registry
South African National Cancer Registry

Tanzania:
Tanzania Cancer Registry

Uganda:
Kampala Cancer Registry

Zimbabwe:
Zimbabwe National Cancer Registry