

Activities, Achievements, and Challenges of PABIN

Abraham Aseffa
PABIN Secretariat

Fourth EDCTP Annual Forum
22-24 October 2007
Ouagadougou



Outline

1. PABIN

- History
- Strategic plan

2. Achievements

- Conferences and training activities
- Secretariat
- National chapters
- Developing collaborations
- Fundraising

3. Challenges

DUPLICATE

ORS/102/35/2373
Registration No. Form S02 (Rule 6)

REPUBLIC OF ZAMBIA

THE SOCIETIES RULES
(Section 7 (1) of Societies Act Cap119)

CERTIFICATE OF REGISTRATION

I HEREBY CERTIFY that:

PAN AFRICAN BIOETHICS INITIATIVE

LUSAKA DISTRICT

this 21ST day of FEBRUARY 20 05 have (has) been duly registered pursuant to and in accordance with the provisions of the Societies Act Cap 119 of the Laws of Zambia and the Regulation made thereunder.

Given under my hand at LUSAKA

This 21ST day of FEBRUARY 20 05

R. SAKALA (Ms)
Registrar

Printed 2002 and Stocked by the Office of the Registrar of Societies



The Pan-African Bioethics Initiative (PABIN)

- **PABIN was founded at a pan-African conference on ethics in health research in January 2001 in Lusaka, Zambia**
 - **Conference organized by WHO/TDR following on an initiative taken by AMVTN (later AMANET) in 1999**
 - **40 participants representing 15 African Countries**
 - **(Benin, Cameroun, Ethiopia, Gabon, Guinea, Ivory Coast, Kenya, Liberia, Morocco, South Africa, Sudan, Tanzania, Uganda, Zambia and Zimbabwe)**
 - **in addition Belgium, France, the Philippines, Switzerland and United States of America were represented.**



PABIN is linked in a global forum

- **Strategic Initiative for Developing Capacity in Ethical Review (SIDCER)**
 - Asia and Western Pacific (FERCAP),
 - former Russian states (FECCIS),
 - Latin America (FLACEIS),
 - Pan African Bioethics Initiative (PABIN)
 - North America (FOCUS).

Pan African Bioethics Initiative

P A B I N

Réseau Panafricain de Bioéthique



PABIN's strategic plan: action items

- Developing an overview of existing ethical review committees within the African Region and maintaining a **registry**
- Developing competent in-country **ethical review systems**
- Contributing a concerted **African voice** to the international discussions on ethics and science in health research
- Assisting national health authorities in Africa with the development of **national guidelines for ethical review**
- Developing educational programs in ethics and GCP that are integrated into **university curricula**
- Establishing national systems for **accrediting** health research ethics review committees in Africa
- Acting as an information exchange and meeting ground between African researchers and ethicists as well as an **interface** between Africans engaged in health research and the international community



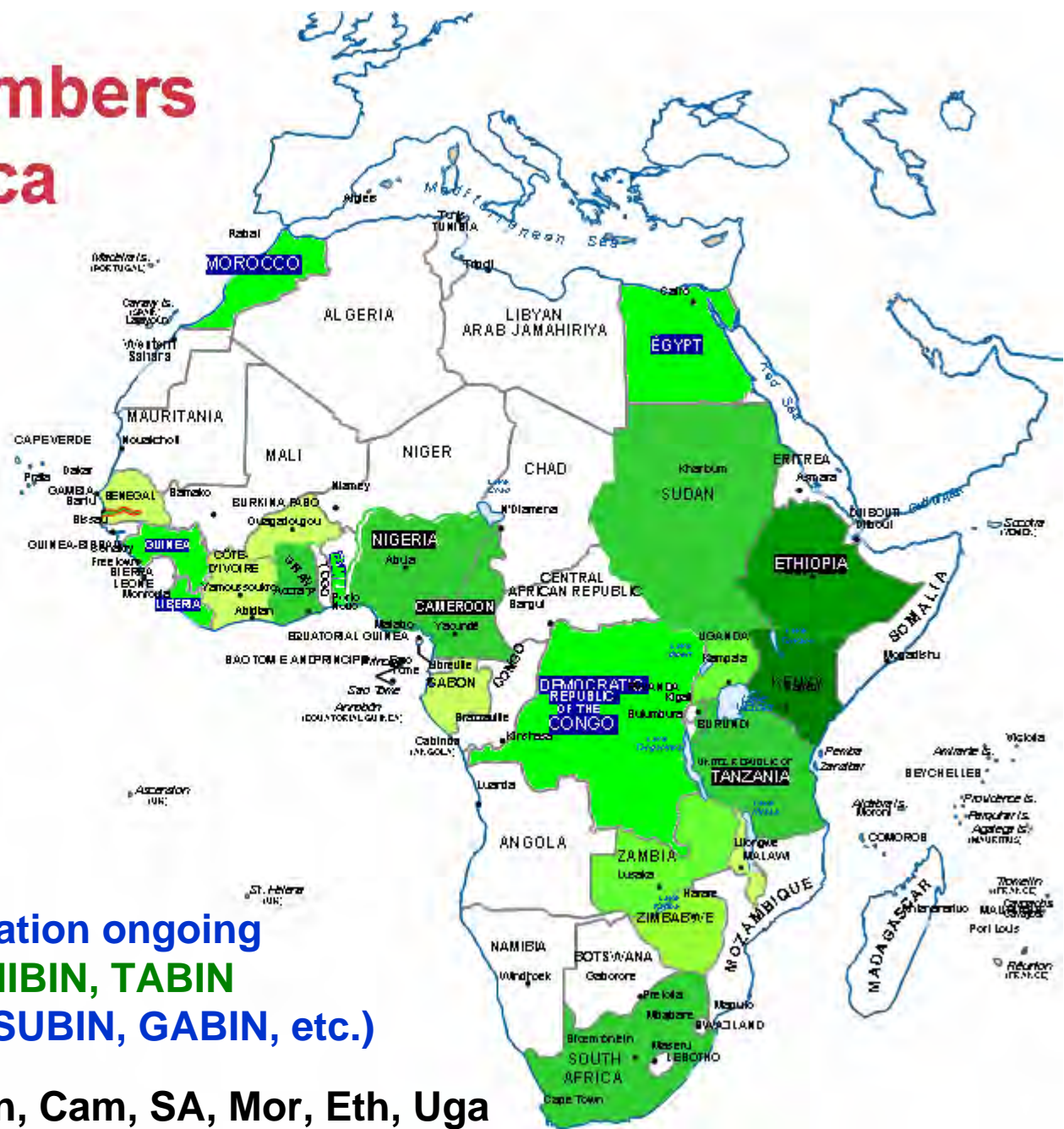
PABIN members in Africa

Membership -
324 members
in 26 countries

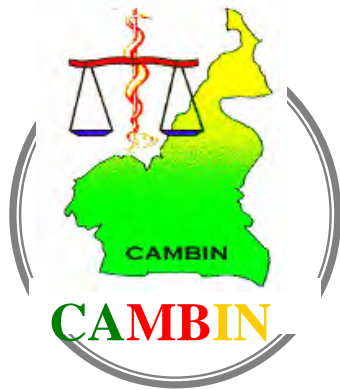
Kenya	51
Ethiopia	50
Nigeria	31
Cameroon	28
Tanzania	24
Ghana	24
Uganda	14
Sudan	26
S. Africa	26

National Chapter formation ongoing
ETBIN, CAMBIN, NIBIN, TABIN
Under formation (SUBIN, GABIN, etc.)

EC: Zam, Tz, Benin, Cam, SA, Mor, Eth, Uga



National Chapter activities: examples



- **Office** in the Biyemassi area of the city of Yaounde at Immeuble Sonkeng, Rond Point Express, Biyemassi, B.P. 31489, Yaounde, Cameroon. Tel/Fax +237-231-2880
 - currently hosting the Yaounde Sub-Hub of the African Malaria Network Trust (AMANET)
 - CAMBIN Ethics Review and Consultancy Committee (ERCC)

Networking and forum building

- US CENTERS FOR DISEASE CONTROL AND PREVENTION (**CDC-CAMEROON**)
- the **FOBANG FOUNDATION**, led by their president, Professor Wilfred Mbacham, and including Steven Smits of the **Albert Schweitzer Fonds**
- On 04/07/2007, **THE CONSTANT GARDENER**, a film about industrialized developed world pharmaceutical research in Africa, was screened at the CAMBIN office

Report by Godfrey Tangwa



National chapters...

ETBIN



- Translation of *WHO/TDR Operational Guidelines for Ethics Committees that review biomedical research* into Amharic (national language)
- National discussion forum on ethical dilemmas:
 - rights of research participants to medical care for incidental findings, HIV care
 - Standards of care for HIV positive patients
- National Review meetings on draft *National Guidelines for ethical review systems in Ethiopia*:
- Support to National Ethical Review Committee

Report by Beyene Petros



Activities: Forum building

- **Communication with Ethics Review Committees in Africa and PABIN members**
 - EC Survey (2003) and ongoing with AMANET (2007)
 - Executive Committee meetings (Cape Town, Addis Ababa, Zanzibar, Blantyre, Addis Ababa)
 - Executive Committee Telephone Conferences
 - E-mail communications with members, secretariat@pabin.org
 - Meetings during Annual Conferences



Annual PABIN Conferences and themes...

- **Developing Ethical Review in Light of Contemporary Issues in Biomedical Research Ethics, Cape Town, 8-9 Sept 2001**
- **Good Ethical Practice in Health Research in Africa, Cape Town, 23-24 Feb 2002**
- **Third Conference in Addis Ababa “*Good Health Research Practices in Africa*”. United Nations Conference Hall, Addis Ababa, Ethiopia, 28-30 April 2003.**
- **Fourth Conference in Yaoundé, Cameroun, “*Millennium Development Goals and Health Research Ethics in Africa*”, June 5-7, 2005**

**Fifth Conference: October 2008
(Call out for venue, deadline Oct 31, 2008)**



PABIN Meeting April 2003



WHO

AU

DR. BETEN PETROS

LE W. MARGIE HAN

PROF. ACHILLE MASSOUGBOUJI

DR. ROSE KINGAMKONO

PROF. C. CHINTU





PABIN Meeting
April 2003

Pan-African Conferences on Ethics



PABIN Yaoundé Meeting June 2006



PABIN Executive Committee in session Addis Ababa, Jan 19-21 2007



Activities: SIDCER Recognition Programme

- **SIDCER Recognition Programme**
 - Launched in Ethiopia in 2006
 - Plans for Tanzania, Kenya, Uganda (WHO/TDR fund)
 - Plans for West and Southern Africa (EDCTP/other funders/?)
- **Objective:**
 - to measure and provide accountability for the quality and effectiveness of ethical review worldwide.
 - A SIDCER recognition certificate provided to an IRB/IEC is a sign that the highest standards of ethical review in clinical research are being met.

These certificates are a valuable assessment of a country's research abilities and growth



SIDCER Recognized ERCs

1	JIRB	Taiwan	2005
2	The Royal Thai Military, Bangkok	Thailand	2005
3	Changhua Christian Hospital	Taiwan	2005
4	National Soul University, Seoul	S.Korea	April 2006
5	ASAN, Seoul	S. Korea	April 2006
6	National Taiwan University, Taipei	Taiwan	July 2006
7	Chang Gung Memorial Hospital, Taipei	Taiwan	July 2006
8	Veteran General Hospital, Taipei	Taiwan	August 2006
9	Tri Service Hospital, Taipei	Taiwan	August 2006
10	Changhai Hospital, Shanghai	China	August 2006
11	Chulalongkorn University	Thailand	October 2006
12	University of the Philippines	Philippines	December 2006

Source: http://www.sidcer.org/new_web/index.php?group=main&open=recognition.php



Components

- **TOOLS**

- Operational Guidelines for Ethics Committees That Review Biomedical Research

- Operational Guidelines for Surveying & Evaluating Ethical Review Practice

- SIDCER Self assessment tool

- Standard Operating Procedures (SOPs) templates for IEC/IRB

- **ACTIVITIES THAT SUPPORT IEC/IRB RECOGNITION PROGRAMME**

- Human Subject Protection Course

- IEC/IRB SOPs writing workshop

- Site Survey and evaluation



Recognized based on five standards

I. STRUCTURE AND COMPOSITION OF EC

Structure, composition and skills of the EC and staff are appropriate to the amount and nature of research reviewed

II: ADHERENCE TO SPECIFIC POLICIES

EC has appropriate management and operational procedures for optimal and systematic conduct of ethical review

III: COMPLETENESS OF ITS REVIEW PROCESS

EC review protocols and its supporting documents in a timely fashion according to an established procedure to protect the interest of research participants

IV: AFTER REVIEW PROCESS

EC should adequately and effectively communicate its decision to investigators

V. DOCUMENTATION AND ARCHIVING

EC systematically documents and archives its activities for a good time period



Activities: Ethics Committee recognition program



SIDCER Recognition Program: Ethics Committees working on SOPs



Activities...

- **Ethics training**
 - WIRB training to obtain experts for capacity building
 - University curriculum
 - Plan for regular course at the International Training Division, ALERT, Ethiopia
- **Ethics Committee strengthening**
 - Members active in Committees, in training



Activities...

- **Fund raising**
 - EDCTP applications
 - Bill and Melinda Gates Foundation (AMANET/PABIN)
- **Advocacy/Partnership/Networking**
 - African Union
 - WHO/TDR
 - AMANET
 - WHO
 - NEBRA
 - SARETI
 - Ministries of Health
 - National Assembly of Cameroon
 - AHRI/ALERT
 - Ethiopian Science and Technology Agency
 - UNESCO, among others



PABIN EDCTP African Union collaboration for ethics capacity building in Africa



H.E. Dr Pascoal Mocumbi, High Representative of EDCTP, and the PABIN Secretariat at the Office of the Commissioner for Social Affairs, African Union, Addis Ababa





Dr Bernt Lindtjorn

Ms de Oliveira and Dr Makanga with PABIN Chair and Secretary

EDCTP visits to PABIN Secretariat Office in Addis Ababa



EDCTP Site Visit to PABIN 17 9 2007



Challenges and response

- **Funds: minimum of three to five year support**
 - **Network (among/with members and national chapters)**
 - Closer links with ethics initiatives
 - Advocacy for appropriate recognition and support
 - **National Chapters**
 - Support initially; can secure sustainable structures and funding mechanisms on their own
 - More and wider
 - **Executive Committee**
 - General Assembly and elections
 - **Secretariat**
 - Strengthening and networking



Challenges and response

- **Africa is a complex environment with different levels of appreciation of needs for ethics capacity strengthening**
 - Pan African efforts always take long to take root
- **Multiple players**
 - An African voice in ethics requires African leadership and grass root mobilization – it should not be done by proxy
 - PABIN represents an independent African effort for an African Voice and its growing pains are
 - pains of resource limitations: not of vision; and
 - of efforts to be truly independent – with own program and tools, however slow the growth
 - PABIN seeks support to serve as an umbrella and coordinate ethics activities in Africa



Funding to Secretariat

- WHO/TDR for Secretariat support (\$15,000)
- WHO/TDR for SIDCER Recognition Program (\$54,000)
- EDCTP for “Coordinating Office for Ethics in Africa” (85,000 Euros) CG_cb_05_41300a_001
 - Establish an office Done
 - Recruit staff Partially done
 - Register in Ethiopia In progress, with Lawyer
 - Convene exec mtg Done
 - Organize Conference GA/Conference due in Oct '08
 - Newsletter Issue 1 out
 - Contact with members e-mails (messages/documents/calls)
 - Website www.pabin.org
 - Support Chapters Partially done



Acknowledgement

- WHO/TDR
- SIDCER/FERCAP
- AMANET
- EDCTP
- World Health Organization
- African Union
- Ministry of Health, Ethiopia
- National Assembly of Cameroun
- Armauer Hansen Research Institute/ALERT
- ETBIN, CAMBIN, NIBIN, TABIN
- Ethiopian Science and Technology Agency
- UNICEF
- Western Institutional Review Board
- And many other contributors to the Conferences Organized by PABIN over the years



www.pabin.org





Workshops with PABIN participation: 2001-...

- Workshop of **Ethics Review Committees in Africa** (Lusaka, Zambia 29-31 January 2001);
- Workshops on Ethics in Health Research in Africa:
 - » Kisumu, Kenya, 23-27 April 2001;
 - » Addis Ababa, Ethiopia 10-12 December 2001,
 - » Khartoum, Sudan 12-16 January 2003, and
 - » Yaounde, Cameroon 15-19 September 2003.
- Combined Training Workshop on **Health Research Ethics and GCP**, Pretoria, South Africa, 22-26 July 2002.
- Combined Training Workshop on **Health Research Ethics and GCP for Francophone African Countries**, Libreville, Gabon 30 September to 4 October 2002



Workshops with PABIN participation:...

- Workshop on **Standard Operating Procedures for Ethics Review of Health Research in Africa**, Entebbe, Uganda, 17-21 February 2003.
- Workshop on **GCP for African Clinical Monitors**, Ouagadougou, Burkina Faso, 20-24 October 2003.
- A Pan-African Workshop on **Standard Operating Procedures for the Ethical Review of Health Research**, Makerere University (Entebbe, Uganda, 17-21 February 2003)



Workshops with PABIN participation: ...

- **Ethique et qualité en recherche clinique**, organised by
 - INSERM in collaboration with PABIN, French Institutions, EFGCP, Institut Pasteur, Espace-Ethique Méditerranée, Association pour l'Aide à la Médecine Préventive, Institut de Recherche pour le Développement, Faculté de Médecine Paris Sud (Pari XI), Fondation d'Entreprise GlaxoSmithKline-France (Paris, France, 21-23 October 2002)
- PABIN has also been represented in other workshops and meetings for example:
 - A workshop on **Partnership for Enhancing Human Research Protection** held on 31st May to June 4th 2004, Blantyre, Malawi. A total of 74 participants from 9 African countries (Botswana, Ethiopia, Ghana, Kenya, Malawi, Tanzania, Uganda, Zambia and Zimbabwe attended.
 - A Conference on **Ethical Aspects of Clinical Research in Developing Countries** held on 20-22 March 2002, Accra, Ghana. 48 participants from Benin, Cameroon, Egypt, Ghana, Kenya, Malawi, South Africa, Tanzania, Uganda, and Zimbabwe attended.



Workshops with PABIN participation: -...

- Health Related Biotechnology in Africa: ethical, legal and social implications (ELSI) of transfer and development organized by TDR/WHO in collaboration with West African Bioethics Program; Ibadan, Nigeria, 4-8 April 2006
- AMANET Health Research Ethics Training, Dagem Millennium Hotel, Addis Ababa, Sept 24-28, 2007



National Chapter activities: examples

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