

Health Research Ethics Landscape in Africa over the last decade

... and future outlook

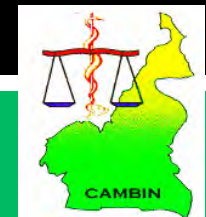
Odile Ouwe Missi Oukem-Boyer, PhD

Director General CERMES (2012 --)

Vice-Chair of CAMBIN (2009 --)



Niamey, Niger
Yaoundé, Cameroon
oukem@gmail.com



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Disclosure

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Health Research
Ethics
Landscape in
Africa over the
last decade

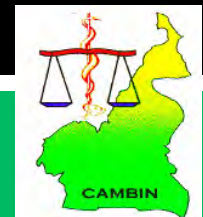
... and future
outlook

Overview, my
view
Not exhaustive,
Based on my
own knowledge
& experience
... and ideas

http://www.3dvf.com/forum/3dvf/Rendu-2/diffraction-decomposition-lumiere-sujet_63_1.htm

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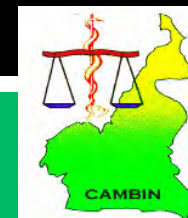
Plan of the presentation

3

1. Global context over the last decade 
2. Health Research Ethics in Africa over the last decade 
3. Looking back in the mirror: lessons learnt 
4. Perspectives for Africa 
5. Conclusion 


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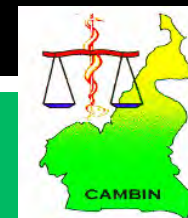
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Health Research Ethics in a global context over the last decade

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✧ U.N. Institutions

- ⌘ WHO's Ethics and Health Initiative (2002) → Department of Ethics and Social Determinants (Global Health Ethics)
- ⌘ United Nations Inter-Agency Committee on Bioethics (UNIACB), under the UNESCO's coordination (2003)

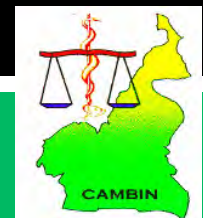
✧ Global Conferences

- ⌘ World Congress of Bioethics (11th Rotterdam, The Netherlands, June 2012)
- ⌘ Biennial Global Summit of National Bioethics Advisory Bodies (9th Carthage, Tunisia, Sept. 2012)
- ⌘ Global Forum on Bioethics in Research, 1999 to 2008 (GFBR10 put on hold)



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Health Research Ethics in a global context over the last decade

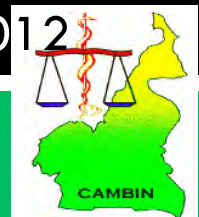
6

✧ Series of texts & booklets

- ⌘ WMA: DoH 2000, clarifications 2002-2004, 2008, 2013
- ⌘ CIOMS guidelines 2002, under revision
- ⌘ UNESCO: Universal Declaration on Bioethics and Human Rights, adopted in 2005
- ⌘ Guideline for Good Clinical Practice: ICH Harmonised Tripartite Guideline. Geneva, International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use, 2006
- ⌘ UNAIDS-WHO: ethical considerations in biomedical HIV prevention trials, 2007, 2012
- ⌘ UNAIDS-AVAC: Good Participatory Practice guidelines for biomedical HIV prevention trials, 2007, 2011
- ⌘ WHO: Guidance on ethics of tuberculosis prevention, care and control, 2010
- ⌘ FHI: The Stakeholder Engagement Toolkit for HIV Prevention Trials, 2012

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Health Research Ethics in a global context over the last decade

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✧ Series of texts & booklets (cont'ed)

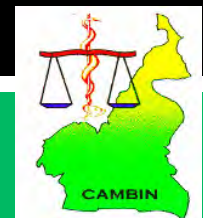
⌘ Nuffield Council Documents (not exhaustive) :

- ⌘ The ethics of clinical research in developing countries: a discussion paper, 1999
- ⌘ The ethics of research related to healthcare in developing countries, 2002
- ⌘ The ethics of patenting DNA, 2002
- ⌘ The ethics of research related to healthcare in developing countries: a follow-up discussion paper, 2005
- ⌘ Critical care decisions in fetal and neonatal medicine: ethical issues, 2006
- ⌘ Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age, 2010



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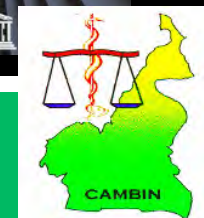


Health Research Ethics in a global context over the last decade

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✧ Series of texts and booklets (cont'd)

- ⌘ WHO: Research ethics committees : basic concepts for capacity-building, 2009
- ⌘ WHO: Standards and Operational Guidance for Ethics Review of Health Related Research on Human Participants, 2011
- ⌘ UNESCO: Guide No.1 Establishing Bioethics Committees, 2005/ Guide No.2 Bioethics Committees at Work: Procedures and Policies, 2005/ Guide No.3 Educating Bioethics Committee, 2005



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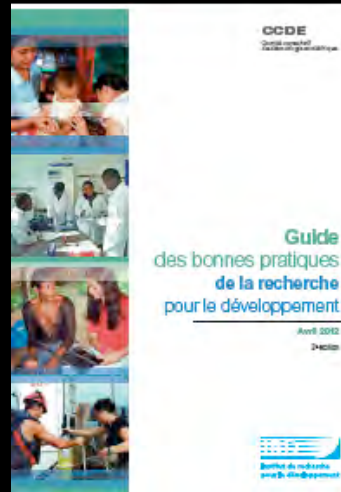


Health Research Ethics in a global context over the last decade

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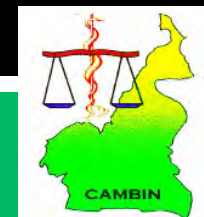
✧ Series of texts and booklets (cont'ed)

- ⌘ ANRS chart of ethical research in developing countries, 2002, 2008
- ⌘ IRD guidelines on good practice in research for development, 2005, 2012
- ⌘ Pasteur Institute chart of ethics, 2009



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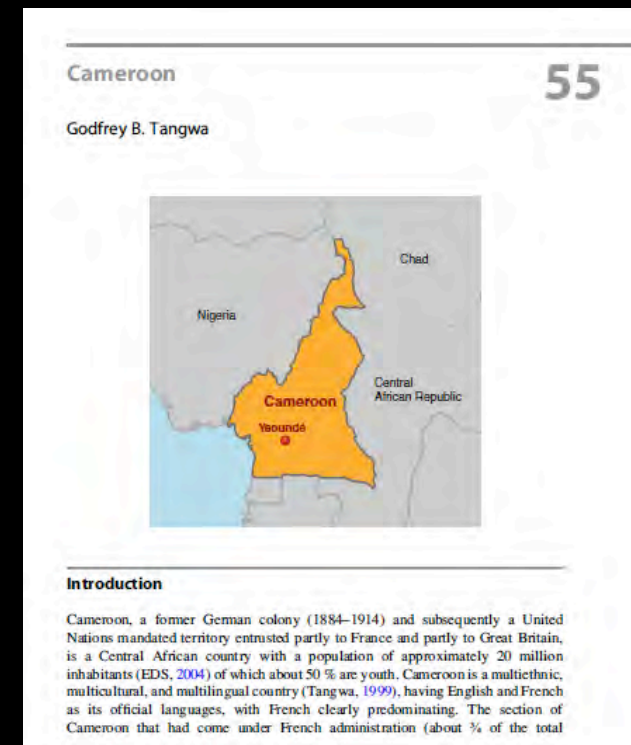
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Between the past and the future (2014)

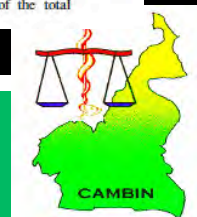


1. Burkina Faso
2. Cameroon
3. Democratic Rep of Congo
4. Egypt
5. Ethiopia
6. Malawi
7. South Africa



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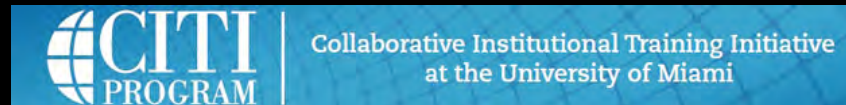




Health Research Ethics in a global context over the last decade

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- ✧ Any other business (from the US)
 - ⌘ Office for Human Research Protections (OHRP)
 - ⌘ Federalwide Assurance (FWA) for the protection of human subjects
 - ⌘ Educational online programs
 - Collaborative Institutional Training Initiative
- “Over 5.5 million CITI Program courses have been completed since 2000”



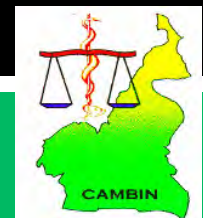
- Family Health International Research ethics training curriculum



remember... not exhaustive...


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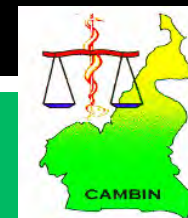
Plan of the presentation

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Institutions/Associations

Key players

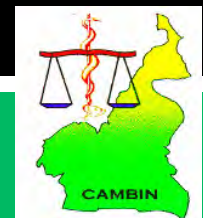
Initiatives-projects

Continental
Regional
Local

Training
Institutional
development
Networking

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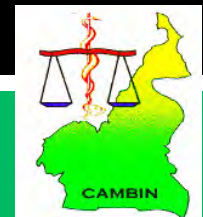
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Education – training & capacity building

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Continental – Institutions - African Malaria Network Trust



(>1000 Africans trained)

Online courses

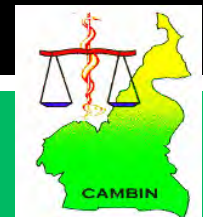
- Basic HRE,
- French version of the Basic HRE,
- Advanced HRE
- Good Clinical Practice (GCP)

Workshops

- Advanced Health Research Ethics (HRE) for investigators
- Harmonization of standard operating procedures for Ethics Review Committees (ERCs)

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Continental –Initiatives- Training and Resources in Research Ethics Evaluation



E-learning modules

(a web-based learning program and certification)

Module 1: Introduction to research

Module 2.1: Research Ethics evaluation

Module 3.1: Informed consent

Module 3.2: Good Clinical Practice

Module 3.3: HIV Vaccine Trial



National supplements

(local experts explain requirements in their country)

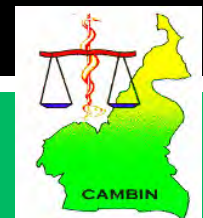
Africa: Burkina Faso, Cameroon, Cote d'Ivoire, Mali, Mozambique

Nigeria, Senegal, Tanzanie

Europe: Switzerland, Germany

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Local – Institutions – University of Kwazulu Natal- School of Psychology

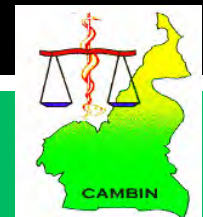


Education & Training in Research Ethics

- South African Research Ethics Initiative (SARETI)
 - Short courses/modular courses
 - Full master programs
 - SARETI African Health Research Ethics Symposium, Durban 2010

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Partnership – Institutions – NIH-Fogarty International Center



Fogarty International Center
Advancing Science for Global Health

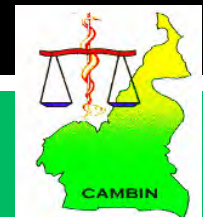
Education & Training in Research Ethics

Stellenbosch University Tygerberg Campus

- Advancing Research Ethics Training in Southern Africa (ARESA, which replaced IRENSA)
 - postgraduate Diploma/Masters level educational program
 - national network for Research Ethics Committee (REC) members

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Partnership – Institutions – NIH-Fogarty International Center (cont'd)



Fogarty International Center
Advancing Science for Global Health

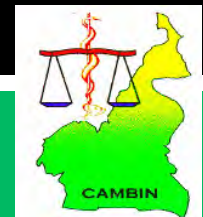
Education & Training in Research Ethics

University of Maryland School of Medicine
Middle East Research Ethics training Initiative
(MERETI)

- Masters degree programs with specialization in Research Ethics
- Online certificate Program
- MERETI program in Research Ethics
- Workshops in the Middle East

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Partnership – Institutions – Vienna School of Clinical Research

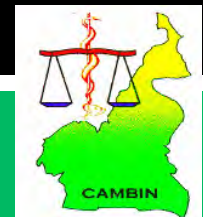


Training in Clinical Research and Ethics

- Kenya
- Lambarene, Gabon (++++)
- Malawi
- South Africa
- Tanzania,

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Local – Initiatives - West African Bioethics



West African Bioethics

funded by: the Fogarty International Center of the
United States' National Institute of Health

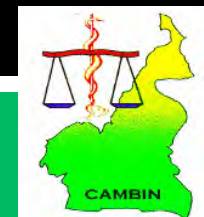
Training in Bioethics

- MSc. in Bioethics
- Online training (CITI program)
- WAB Newsletters
- Discussion forum for members

The screenshot shows the West African Bioethics website. The header includes the title 'West African Bioethics' and a subtitle 'A program for Teaching, Services and Research in International Bioethics'. Navigation links include Home, About WAB, Education, BEOnline Journal, News Center, Events, and For Members. A search bar is present. The main content area features a banner for 'MSc. Bioethics 2013/2014' with text about the admission exercise at the University of Ibadan. Below this is a section for 'Education and Training' with a lightbulb icon. To the right, there is a 'Partners' section listing the College of Medicine at the University of Ibadan, the Fogarty International Center, the National Human Genome Research Institute, and the Dominican Institute. A sidebar on the right contains a 'Recommended' section with a link to 'Are you a Bioethicist?' and a 'Bioethics FAQ' section.

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Selected Publications about training and capacity building-1

J Med Ethics, 2009 Mar;35(3):189-93. doi: 10.1136/jme.2008.025189.

Composition, training needs and independence of ethics review committees across Africa: are the gate-keepers rising to the emerging challenges?

Nyika A, Kilama W, Chilengi R, Tangwa G, Tindana P, Ndebele P, Ikingura J.

African Malaria Network Trust, Dar es Salaam, Tanzania. anyika@amanet-trust.org

Dev World Bioeth, 2009 Dec;9(3):149-56. doi: 10.1111/j.1471-8847.2008.00243.x.

Capacity building of ethics review committees across Africa based on the results of a comprehensive needs assessment survey.

Nyika A, Kilama W, Tangwa GB, Chilengi R, Tindana P.

African Malaria Network Trust, Dar es Salaam 33207, Tanzania.

developing world
bioethics

Developing World Bioethics ISSN 1471-8731 (print); 1471-8847 (online)

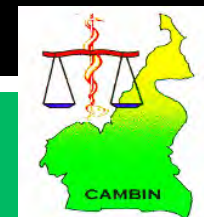
doi:10.1111/j.1471-8847.2009.00266.x

**TRAINING NEEDS ASSESSMENT IN RESEARCH ETHICS EVALUATION
AMONG RESEARCH ETHICS COMMITTEE MEMBERS IN THREE AFRICAN
COUNTRIES: CAMEROON, MALI AND TANZANIA**

JÉRÔME ATEUDJIEU, JOHN WILLIAMS, MARIE HIRTLE, CÉDRIC BAUME,
JOYCE IKINGURA, ALASSANE NIARÉ AND DOMINIQUE SPRUMONT

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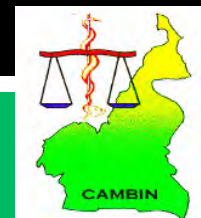
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Selected Publications about training and capacity building-2



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Selected Publications about training and capacity building-3

Camb Q Healthc Ethics. 2013 Jan;22(1):110-9. doi: 10.1017/S0963180112000436.

Role of e-learning in teaching health research ethics and good clinical practice in Africa and beyond.

Chilengi R, Nyika A, Tangwa GB, Noor RA, Ramadhani SW, Bosomprah S, Kilama WL.

University of Oxford, UK.

PMID: 23206363 [PubMed - indexed for MEDLINE]

Downloaded from jme.bmj.com on August 25, 2013 - Published by group.bmj.com
JME Online First, published on August 19, 2013 as 10.1136/medethics-2013-101572

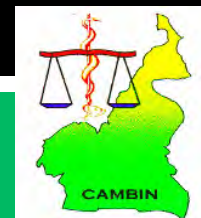
Brief report

Consensus standards for introductory e-learning courses in human participants research ethics

John R Williams,¹ Dominique Sprumont,² Marie Hirtle,³ Clement Adebamowo,^{4,5,6}
Paul Braunschweiler,⁷ Susan Bull,⁸ Christian Burri,⁹ Marek Czarkowski,¹⁰
Chien Te Fan,¹¹ Caroline Franck,¹² Eugenijus Gefenas,¹³ Antoine Geissbuhler,¹⁴
Ingrid Klingmann,¹⁵ Bocar Kouyaté,¹⁶ Jean-Pierre Kraehenbuhl,¹⁷ Mariana Kruger,¹⁸
Keymanthri Moodley,¹⁹ Francine Ntoumi,²⁰ Thomas Nyirenda,²¹ Alexander Pym,²²
Henry Silverman,²³ Sara Tenorio²⁴

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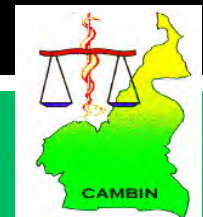
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Institutional Development

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Health Research Ethics in Africa over the last decade

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Continental –Initiatives- Networking for Ethics on Biomedical Research in Africa



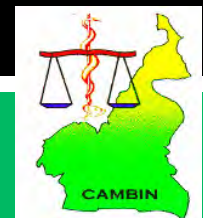
NEBRA countries:

Benin, Burkina Faso, Cameroon, Central African Republic, Congo, Côte d'Ivoire, Democratic Republic of Congo, Gabon, Gambia, Ghana, Mali, Nigeria, Senegal, and Togo.

Goal: Situation of legislation and organization of RECs

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Continental – Institutions- European and Developing Countries Clinical Trial Partnership



Projects funded (n=75 in 3 categories)

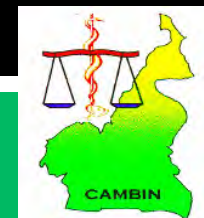
- Training (TRREE, ERECCA)
- Institutional development (NEC, CAMBIN, OCEAC) +++
- Networking (MARC)

Anglophone > Francophone > Lusophone



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Local –Initiatives- West African Bioethics

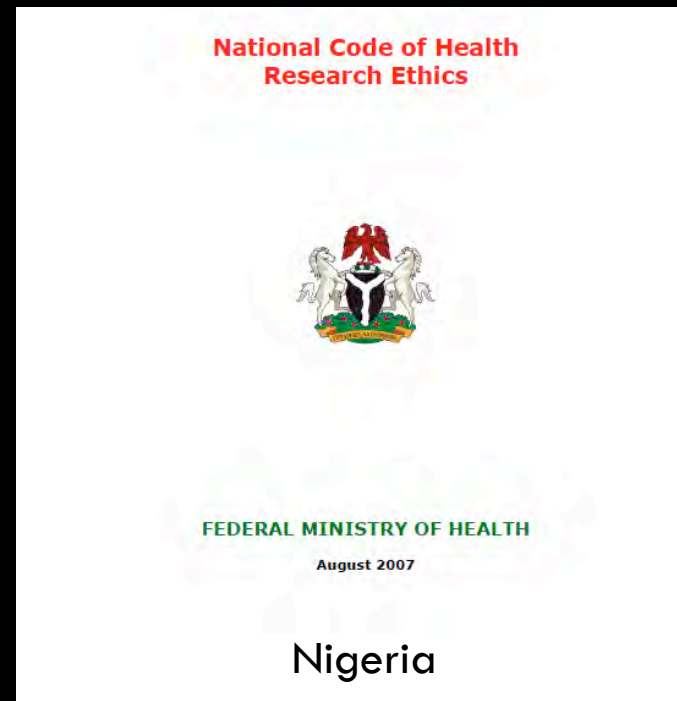


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United States' National Institute of Health

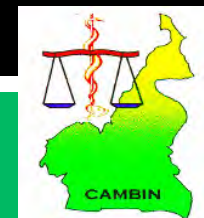
Support to the federal Ministry of
health

- Adoption of the National Code of
Health Research Ethics



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Health Research Ethics in Africa over the last decade

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Selected Publications related to institutional development -1

OPEN ACCESS Freely available online January 2007 | Volume 4 | Issue 1 | e3 PLOS MEDICINE

Policy Forum

The Structure and Function of Research Ethics Committees in Africa: A Case Study

Nancy E. Kass*, Adnan Ali Hyder, Ademola Ajuwon, John Appiah-Poku, Nicola Barsdorf, Dya Eldin Elsayed, Mantoa Mokhachane, Bavon Mupenda, Paul Ndebele, Godwin Ndossi, Bornwell Sikateyo, Godfrey Tangwa, Paulina Tindana

Sleem et al. BMC Medical Ethics 2010, 11:12
<http://www.biomedcentral.com/1472-6939/11/12>

BMC Medical Ethics

RESEARCH ARTICLE Open Access

Identifying structures, processes, resources and needs of research ethics committees in Egypt

Hany Sleem¹, Samer S El-Karnary² and Henry J Silverman*²

Ethics Committee Self-Assessment 85

DEVELOPMENT OF AN ACCESSIBLE SELF-ASSESSMENT TOOL FOR RESEARCH ETHICS COMMITTEES IN DEVELOPING COUNTRIES

HANY SLEEM
National Hepatology and Tropical Medicine Research Institute, Egypt

REHAB ABDELHAI AHMED ABDELHAI
Cairo University, Egypt

IMAD AL-ABDALLAT
Jordan University, Jordan

MOHAMMED AL-NAIF
King Saud University, Saudi Arabia

HALA MANSOUR GABR

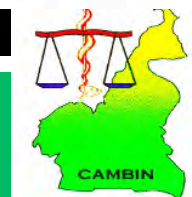
pragmatic aspects of human subjects protection, is based on international standards, is straightforward in its completion, and its items are relevant to the administrative processes that exist in many RECs in the developing world.

KEY WORDS: research ethics committees, developing countries, human subjects protections, self-assessment, accreditation, Institutional Review Board

Received: May 20, 2010; revised: July 5, 2010

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Selected Publications related to institutional development -2

Special Section: Bioethics beyond Borders 2011

Sprinting Research and Spot Jogging Regulation: The State of Bioethics in Cameroon

GODFREY B. TANGWA and NCHANGWI SYNTIA MUNUNG

Cambridge Quarterly of Healthcare Ethics (2011), 20, 356–366.
© Cambridge University Press 2011.
doi:10.1017/S0963180111000041

Bioethica Forum / 2013 / Volume 6 / No. 1

FOCUS: DEVELOPING WORLD BIOETHICS

Point de vue

Ethique dans les pays en développement, éthique en développement

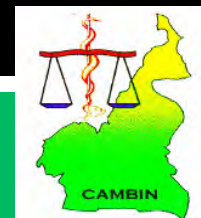
Dominique Sprumont^a, Jérôme Ateudjieu^b

^a Professeur en droit et directeur-adjoint de l'Institut de droit de la santé, Université de Neuchâtel

^b MD, MPH, enseignant au département des sciences biomédicales, Université de Dschang, Cameroun

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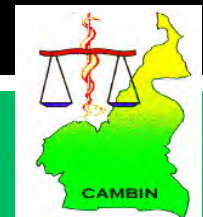
Health Research Ethics in Africa over the last decade

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Networking

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Health Research Ethics in Africa over the last decade

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Continental – Institutions – Pan African Bioethics Initiative



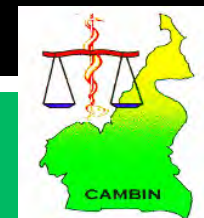
Ambitious Strategic Plan

- Developing & maintaining a registry of existing ERCs
- Developing ethical review capacity
- Developing guidelines for ethics review
- Developing educational programs in ethics and GCP and integrating them into University curricula
- Contributing a concerted African voice to the international discussions on both ethics and science in health research
- Being an exchange platform for African researchers and ethicists

Various Conferences

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Health Research Ethics in Africa over the last decade

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National chapters of PABIN

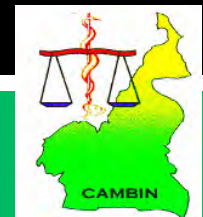


- ETBIN



- CAMBIN

- NIBIN ? TABIN ? SUBIN ? GABIN ?





Health Research Ethics in Africa over the last decade

Continental – Institutions- Council on Health Research for Development



Project

- Mapping African Research Ethics Review Capacity (MARC)

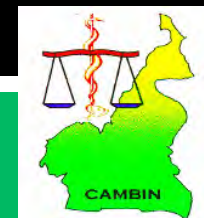
Symposium/Conference/Forum



- First African Conference for Administrators of Research Ethics Committees, Kasane, 2011
- Global Forum on Health Research, 2012

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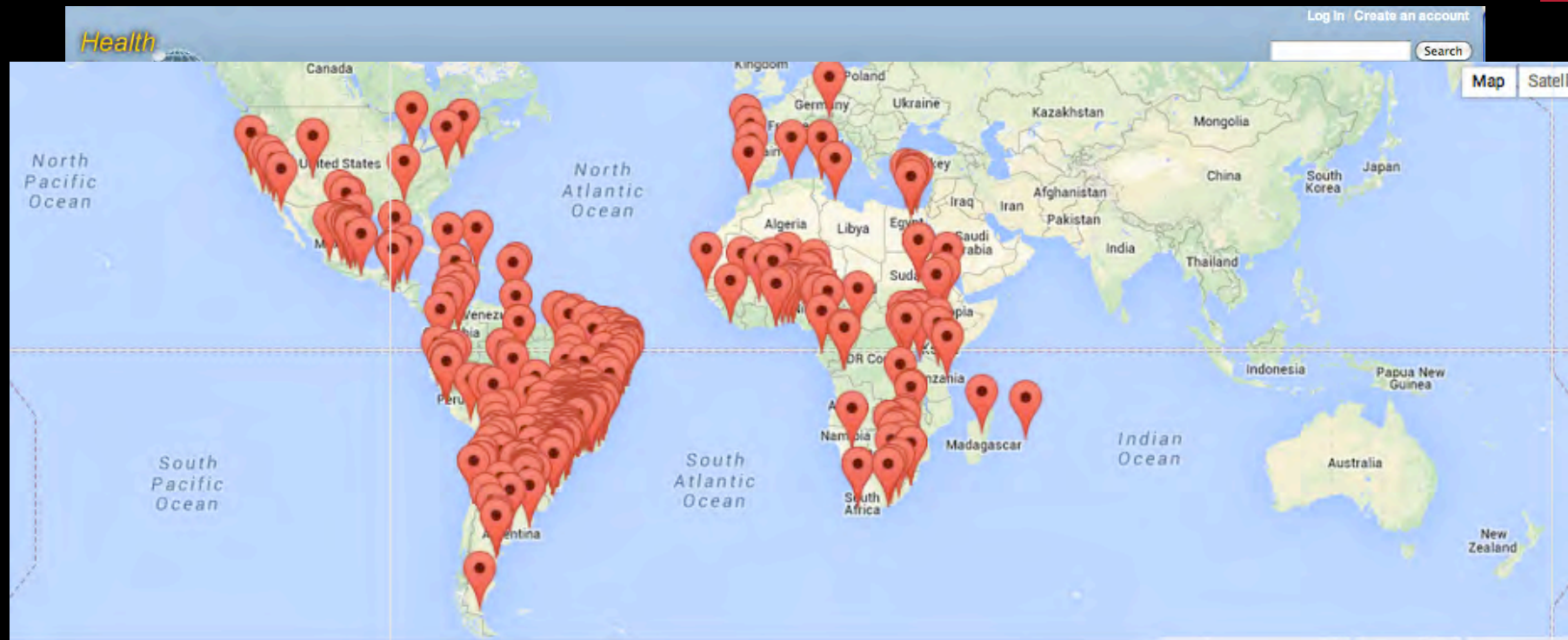




Health Research Ethics in Africa over the last decade

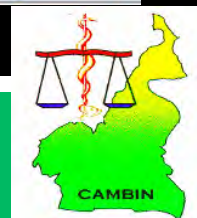
35

Research Ethics Web
Mapping African Research Ethics Review Capacity



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Health Research Ethics in Africa over the last decade

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Local – Institutions – University of Kwazulu Natal- School of Psychology

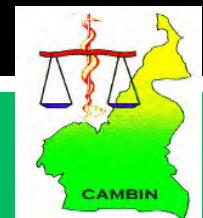


Working groups

- Ethics, Law and Human Rights (ELH) working group of AAVP
- HIV AIDS Vaccines Ethics Group (HAVEG)

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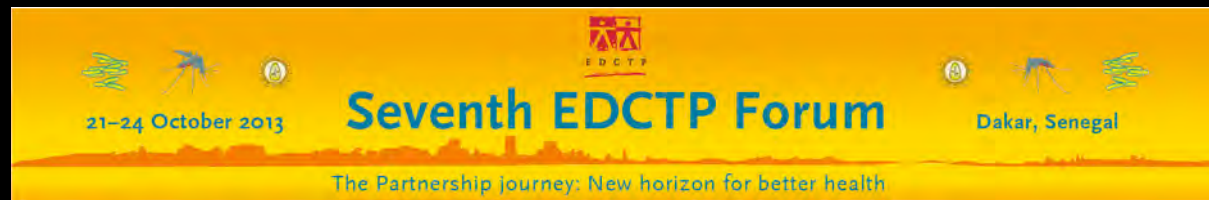
37

Continental – Institutions- European and Developing Countries Clinical Trial Partnership



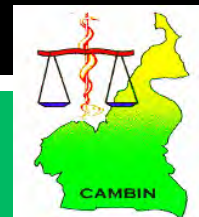
Forum

- 1st Rome, 2004
- 2nd Durban, 2005
- 3rd, Stockholm, 2006
- 4th, Ouagadougou, 2007
- 5th, Arusha, 2009
- 6th, Addis Ababa, 2011
- 7th...



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Networks of Excellence

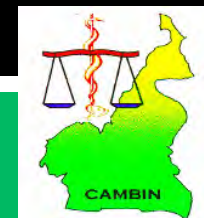
- WANETAM
 - Senegal, Guinea, B-Faso
- CANTAM
 - Gabon, Cameroon, Rep of Congo
- EACCR
 - Kenya, Ethiopia, Tanzania
- TESA
 - South Africa, Botswana, Mozambique

remember... not exhaustive...

Miiró et al. BMC Public Health 2013, 13:258 doi:10.1186/1471-2458-13-258

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Selected Publications related to Networking

developing world
bioethics

MAPPING AFRICAN ETHICAL REVIEW COMMITTEE ACTIVITY ONTO CAPACITY NEEDS: THE MARC INITIATIVE AND HRWEB'S INTERACTIVE DATABASE OF RECS IN AFRICA

CAREL IJSSELMUIDEN¹, DEBBIE MARAIS^{1,*}, DOUGLAS WASSENAAR², BOITUMELO MOKGATLA-MOIPOLA³

Article first published online: 18 APR 2012
DOI: 10.1111/j.1471-8847.2012.00325.x
© 2012 Blackwell Publishing Ltd.

Issue

bioethics

Developing World Bioethics
Volume 12, Issue 2, pages
74–86, August 2012

Miiró et al. *BMC Public Health* 2013, 13:258
<http://www.biomedcentral.com/1471-2458/13/258>



RESEARCH ARTICLE

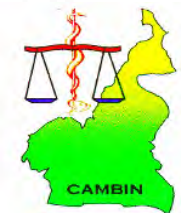
Open Access

EDCTP regional networks of excellence: initial merits for planned clinical trials in Africa

George M Miiró^{1*†}, Odile Ouwe Missi Oukem-Boyer^{2,5†}, Ousmane Sarr³, Maerangis Rahmani⁴, Francine Ntoumi^{2,6}, Keertan Dheda⁴, Alexander Pym⁴, Souleymane Mboup³, Pontiano Kaleebu¹ and On behalf of the NoEs' programme

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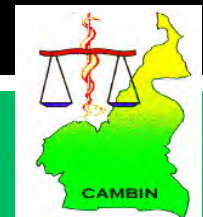
Health Research Ethics in Africa over the last decade

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Health Research Ethics debate

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Health Research Ethics in Africa over the last decade

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Selected Publications related to « HRE debate »

Developing World Bioethics ISSN 1471-8731 (print); 1471-8847 (online)
Volume 7 Number 1 2007 pp 25–34

doi:10.1111/j.1471-8847.2006.00157.x

ETHICAL AND REGULATORY ISSUES SURROUNDING AFRICAN TRADITIONAL MEDICINE IN THE CONTEXT OF HIV/AIDS

ACEME NYIKA

Malawi Medical Journal; 24 (3):65-68 September 2012

View Point: Ethical dilemmas in malaria vector research in Africa: Making the difficult choice between mosquito, science and humans.

P Ndebele¹, R Musesengwa²

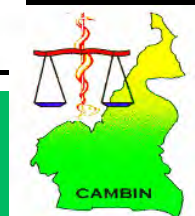
1.HJF-DAIDS, Bethesda, USA

2. Medical Research Council of Zimbabwe

countries by AMANET Trust between 2007-2009. During these focus group discussions, participants were requested to describe and discuss practices in their own institutions. Subsequently observations were made by the authors during

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Health Research Ethics in Africa over the last decade

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Selected Publications related to « HRE debate »

Journal of Empirical Research on Human Research Ethics, pp. 93–97. PRINT ISSN 1556-2646, ONLINE ISSN 1556-2654. © 2011 BY JOAN SIEBER.

Health Research in Cameroon 93

HOW OFTEN ARE ETHICS APPROVAL AND INFORMED CONSENT REPORTED IN PUBLICATIONS ON HEALTH RESEARCH IN CAMEROON? A FIVE-YEAR REVIEW

NCHANGWI SYNTIA MUNUNG
University of Buea, Cameroon and Cameroon Bioethics Initiative (CAMBIN)

CHI PRIMUS CHE
University of Pretoria, South Africa and CAMBIN

ODILE OUWE-MISSI-OUKEM-BOYER
Centre International de Référence Chantal Biya, Yaoundé Cameroon and CAMBIN

GODFREY B. TANGWA
University of Yaoundé I, Cameroon and CAMBIN

today the exact number is unknown. In 2006, the Network for Ethics on Biomedical Research in Africa (NEBRA) reported that the number of RECs operating in Cameroon was of dubious reliability, based on the available data at the time. Effa et al. (2007) had identified only two RECs in Cameroon, while a recent survey (personal communication) identified 14. Training in research ethics in Cameroon is mainly in the form of workshops; research ethics is not part of the curriculum of universities in Cameroon.

International guidelines (CIOMS, 2002; World Medical Association's Declaration of Helsinki, 2008) strongly advocate the submission of research protocols to a REC for review.



Research article

Highly accessed

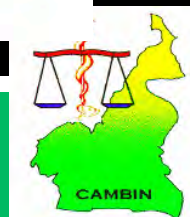
Open Access

Are students kidding with health research ethics? The case of HIV/AIDS research in Cameroon

Nchangwi Syntia Munung^{1,2,5}, Godfrey B Tangwa^{3,5}, Chi Primus Che⁵, Laurent Vidal⁴ and Odile Ouwe-Missi-Oukem-Boyer^{2,5,*†}

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Health Research Ethics in Africa over the last decade

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Selected Publications related to « HRE debate »

developing world
bioethics

Developing World Bioethics ISSN 1471-8731 (print); 1471-8847 (online)
Volume 11 Number 3 2011 pp 120-127

doi:10.1111/j.1471-8847.2011.00305.x

ETHICS OF HUMAN GENETIC STUDIES IN SUB-SAHARAN AFRICA: THE CASE OF CAMEROON THROUGH A BIBLIOMETRIC ANALYSIS

AMBROISE WONKAM, MARCEL AZABJI KENFACK, WALINJOM F.T. MUNA AND
ODILE OUWE-MISSI-OUKEM-BOYER

developing world
bioethics

Developing World Bioethics ISSN 1471-8731 (print); 1471-8847 (online)

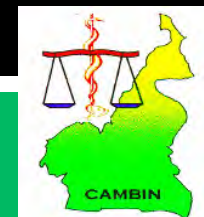
doi:10.1111/dewb.12020

COMMUNITY MEMBERS' ENGAGEMENT WITH AND INVOLVEMENT IN GENOMIC RESEARCH: LESSONS TO LEARN FROM THE FIELD

MORENIKE O. FOLAYAN, KOLAWOLE S. OYEDEJI AND OLAWUNMI A. FATUSI

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Plan of the presentation

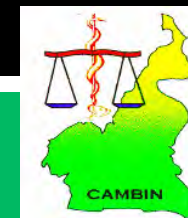
44

1. Global context over the last decade
2. Health Research Ethics in Africa over the last decade
3. Looking back in the mirror: lessons learnt
4. Perspectives for Africa
5. Conclusion



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Looking back in the mirror : lessons learnt

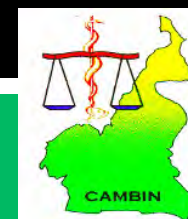
45

« Thinking ahead of course requires looking back, what have we learned in the past, which lessons have we not learned, what can contemporary bioethics show us for tomorrow ».

<http://bioethicsrotterdam.com/>

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Looking back in the mirror : lessons learnt

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Regulatory and ethics
environment: difficulties and
challenges

Facilator/Rapporteur
Sodiomon Sirima(PB)
Aissatou Toure(DCCC)

EDCTP 4th Forum

2007 in Ouagadougou,

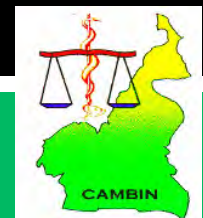
« **Some** achievements in term of awareness,
capacity building, international debate,
networking »

2013

« **Significant/Strong** achievements in term of
awareness, capacity building, international
debate, networking

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Looking back in the mirror : lessons learnt

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EDCTP 4th Forum in Ouagadougou,

ISSUES RAISED

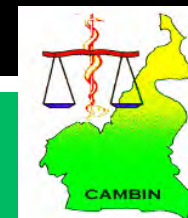
- Duplication of activities and lack of information
- Diversity of systems in the management and regulations of CT
- Scope of ERC versus NRA
- Inadequate and non sustainable funding of ERC activities
- Lack of sufficient expertises for evaluation and monitoring CT
- Inadequate legislation and regulation

Recommandations

- Improve coordination and information between stakeholders and joint activities
- Collect and dissimination of information on on going activities (training, networks, fundings, ...)
- Harmonization needed but uniformisation to be avoided
- Continuation of support of networking
- Developing of harmonized SOP's and regulations for ERC's and NRA's
- Clarification of functions and coordination needed between ERC's and NRA's
- Provide tools and guidelines in different languages
- Advocacy for sustainable fundings for ERC
- Strengthening capacities of NRA and ERC to be continued

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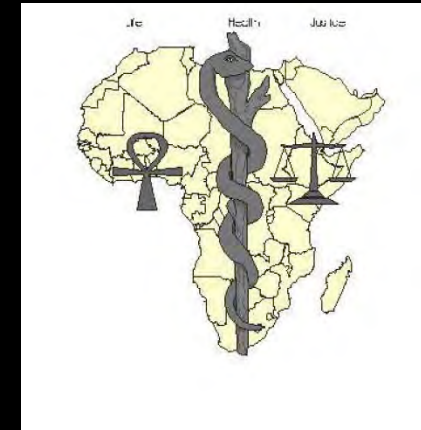
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Looking back in the mirror : lessons learnt

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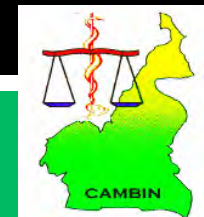


SIDCER : Strategic Initiative for
Developing Capacity in Ethical Review

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SIDCER

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Looking back in the mirror : lessons learnt

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What has positively increased

Ethics's awareness

Amount of training on (Basic and Advanced)
Health Research Ethics (& Good Clinical Practice)

Number of African countries with formalized ethics
committees
(and with Research Ethics review capacity)

Number of initiatives/projects dealing with Health
Research Ethics

What still need to be improved

Legislation governing HRE (very little legislation or
it exists but not applicable or in progress or
inconsistent)

Professionalization of training (integration of
ethics programs into university curricula)

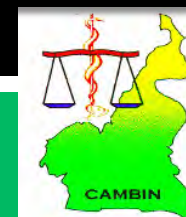
Professionalization of Research Ethics
Committees / Administrators of RECs

Landscape of Ethics Committees in Francophone
Africa

Advocay at the political level (combined with
advocacy on clinical research and trials)


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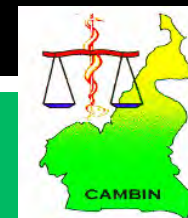
Plan of the presentation

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1. Global context over the last decade
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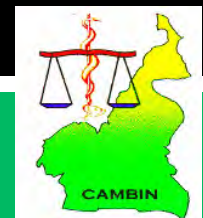




Perspectives for Africa

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- Research Ethics Committee “universal coverage”
 - Every country should have a REC because health research can be carried out everywhere
 - A country with no REC is put at risk of unethical research
 - No blank country should be tolerated
 - Let's see how it works with the OCEAC example
- African Accreditation Body (*FWA-like* for Africa)
- Centralized registry of clinical trials and clinical research
- All Editors of Health medical journals : require to document Ethics approval AND Administrative authorization of research





Perspectives for Africa

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- H3Africa initiative: Human Heredity and Health in Africa
 - ▣ Informed Consent : one or two steps?
 - ▣ Community engagement
 - ▣ Biobanking / Biorepository (Abuja, Stellenbosch)
 - ▣ Cell lines: immortalization of cells of individuals for future use
 - ▣ Education of Ethics Committees around these issues

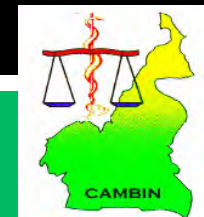
2012-2016



*Genetics, genomics,
Molecular biology,
phylogeny, population
genetics bioinformatics
etc...*

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Antwerp, Belgium http://www.h3africa.org/ethics_governance_resource sharing.cfm

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Perspectives for Africa

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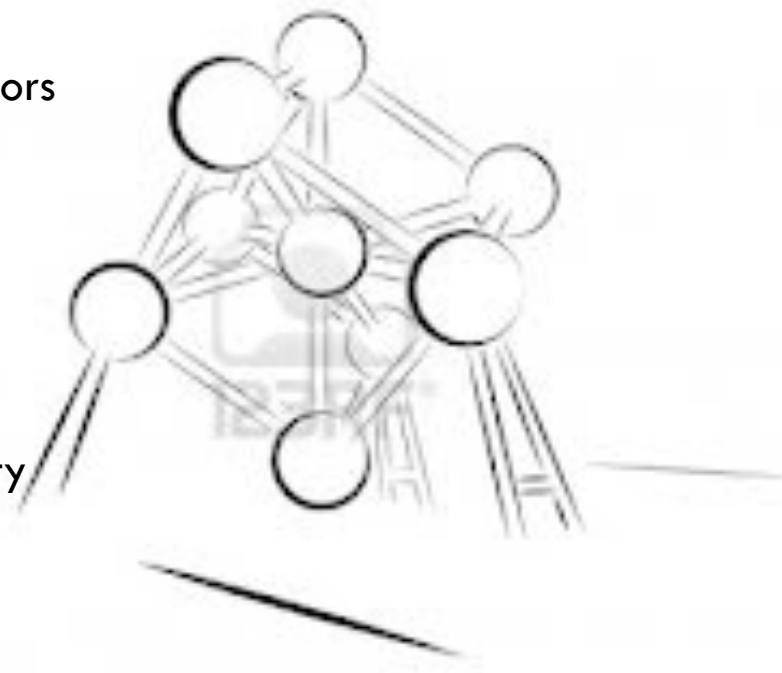
Policy makers

Investigators

RECs

NRAs

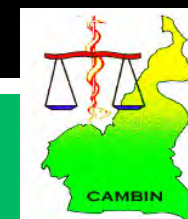
Community



http://nl.123rf.com/photo_14396754_silhouet-van-atomium-bouw-gea-soleerd-op-wit--vector.html

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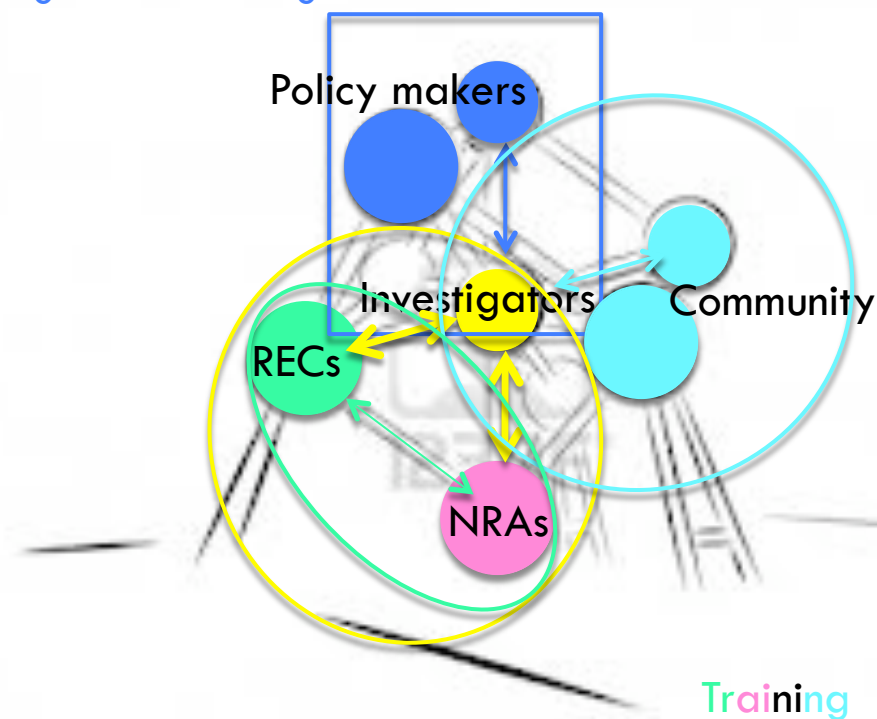




Perspectives for Africa

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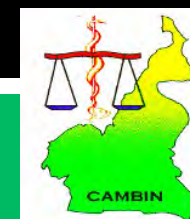
High Level meeting



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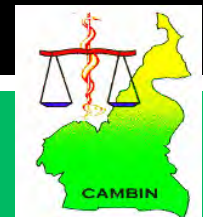
Perspectives for Africa

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- Collaborative (and multidisciplinary) research/Externally sponsored research
 - ▣ Dual ethics approval
 - ▣ Fair negotiation (data sharing, material transfer agreement, authorship)

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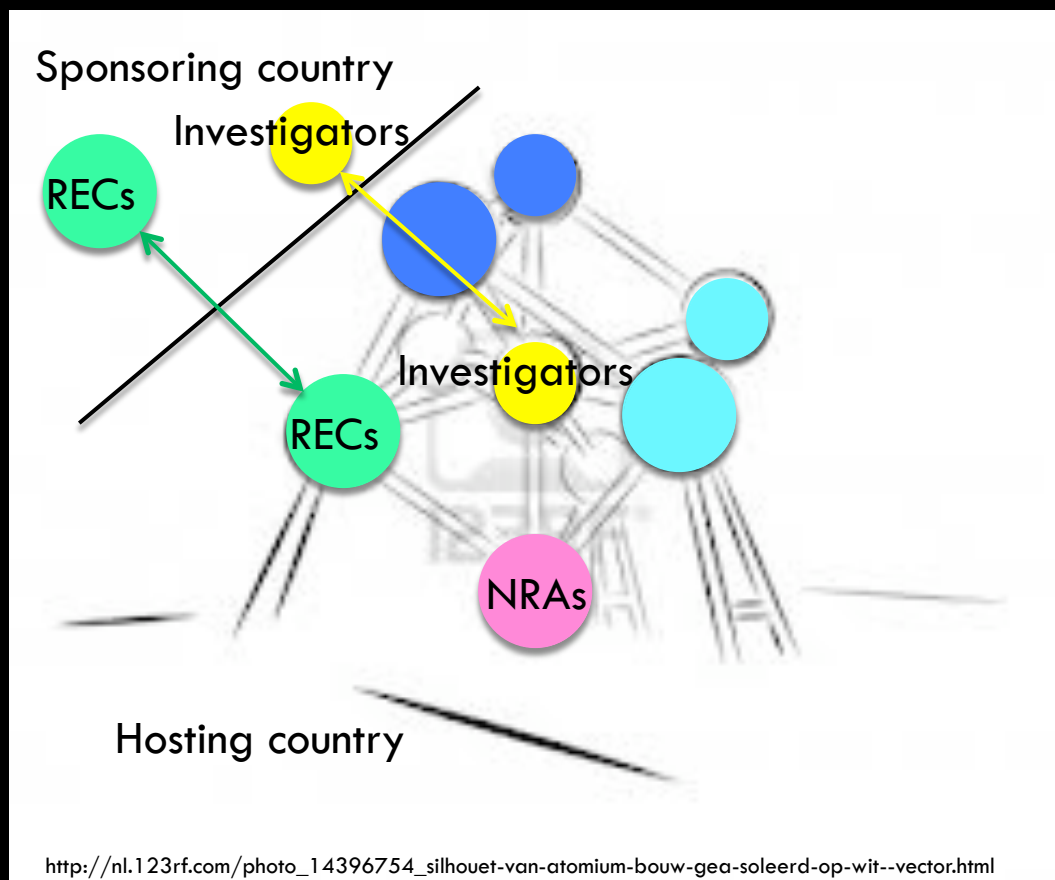
Cameroon **Bioethics Initiative** (CAMBIN)





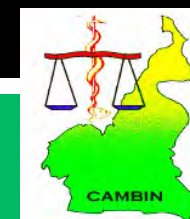
Perspectives for Africa

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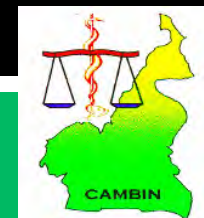


Conclusion

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What else EDCTP could do?

- Biennial Global Summit of National Bioethics Advisory Bodies
 - ▣ Fellowship for representatives of national ethics committees
- Advocacy for a greater participation of Africa in the revision of texts (DoH, CIOMS, UNESCO), including francophone (& lusophone) Africa
- EDCTP award for outstanding African ethicists (irrespective of age)?





Conclusion

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TRREE:

- National supplement to be expended to all African Countries
- EDCTP/us to promote this training tool (requested for applicants)

SAREN:

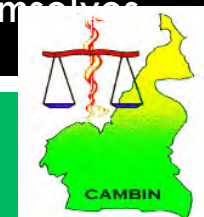
Book to be provided to African Ethics Committees
To be translated in French and Portuguese
EDCTP/us to promote this tool

MARC:

To be expended to mapping of NRAs
To be translated in French and Portuguese and Arabic
Appropriation and update by RECs themselves

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Conclusion

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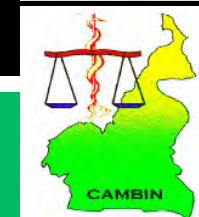


Godfrey B. Tangwa
Nchangwi Syntia Munung
Francine Ntoui
Dominique Sprumont
Mariana Kruger
Marie-Charlotte Bouesseau
Aceme Nyika
Tom Nyirenda
Pierre Blaise Matsiegui
Honoré Ntsiba
Carel IJsselmuiden
Doug Wassenaar
Boitumelo Moipolai
Mary Kasule
Azza Saleh Radwan
Evelyn Anane

Thomas Michel Anana
Armand Nkwescheu
Chi Primus Che
Walinjom Muna
Aissatou Touré
Sodiomon Sirima
Nuraan Fakier
Elizabeth Bukusi



remember... not exhaustive...



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