

**Council on Health Research for Development (COHRED)  
South African Research Ethics Training Initiative (SARETI)**



**Supporting Health Research in Africa:  
'mapping' ethics review and drug regulatory capacity  
-  
the MARC project**

Carel IJsselmuiden, Danny Edwards, Julia Goodall, Douglas  
Wassenaar, Ghaiath Hussein

**EDCTP Forum**  
Arusha, 12-14 October 2009

# overview

1. background
2. the MARC project
3. Health Research Web (*HRWeb*)
4. what can *HRWeb* & MARC do for you ?

# background (1)

- health research is key to health, equity and development
- EDCTP is committed to funding clinical trials and to develop research capacity in the process
- to achieve these goals – ethics review and drug regulatory capacity is essential
- there is great variability and lack of information on this across Africa

# background (2)

- thus ... there is a need to 'map':
- but 'maps' have problems:
  - they are quickly out of date (*'single use' tool*)
  - lack of ownership (*those who 'map' are usually not the same as those whose work is being 'mapped'*)
  - rarely include capacity information
  - focus is on 'accuracy' rather than on the map as a management tool

# MARC (1)

- MARC ('Mapping' African Review Capacity) is a 3-year EDCTP funded project with the aim of creating an African 'map' of:
  - i. research ethics review capacity*
  - ii. research ethics review capacity building efforts*
  - iii. drug regulatory authorities / mechanisms*
  - iv. which itself supports ethics review capacity building*
  - v. and one which is more likely to remain up-to-date*

# MARC (2)

- MARC ('Mapping' African Review Capacity) is implemented through a partnership between
  - Council on Health Research for Development (COHRED), Geneva, Switzerland
    - PI : Carel IJsselmuiden
  - South African Research Ethics Training Programme (SARETI), University of KwaZulu-Natal, Pietermaritzburg, South Africa
    - Co-PI : Doug Wassenaar

# MARC (3)

- Stage 1:
  - develop a ‘self-updating’ map
- Stage 2:
  - the platform is populated, used, cross-linked
  - analysis of specific needs – to focus support
- Stage 3:
  - lead up to an African discussion on African standards and accreditation mechanisms

# MARC (4)

- the MARC project aims will – *with your help and that of many others* – be achieved through COHRED’s new ***Health Research Web*** platform –
  - web-based platform for health research system information and management
  - focus on countries
  - ‘semi-interactive’ / with protected and ‘wiki-’ components ...
  - user extendable, expandable ...
  - HRWeb “2.0” started on 1 September 2009



# *Health Research Web* (1)

- ***Health Research Web*** platform –
  - It is a ‘platform’ – not a ‘database’
    - you can use it for your own purposes
    - some sections are ‘closed’ – information can only be entered and changed by institutions that have an agreement with *HRWeb*
    - other sections are ‘open’ – e.g. discussion pages, and topical subjects
    - like ‘wikipedia’ – it will get better & more useful, the more it is being used :
    - difference between ‘user’ and ‘contributor’ is blurring :
    - quality control is dependent on use – and various other measures

# *Health Research Web* (3)

- ***Health Research Web*** platform –
  - programmed using ‘open source’ approach and public domain software
    - licence cost is not an issue for use - in principle
  - provides basic analyses and cross-tabulations, and encourages users to go further and share this
  - encourages downloading for further analyses
  - was inspired on the Directorate of Science & Technology of the Ministry of Health, Brazil, research project information system
    - *... tried and tested*



### What is HRWeb?



Click on country of interest or select from the dropdown menu:

 ▾
 ▾

[How to get started?](#)

#### Users of this site

- Governments
- Research & Academic Institutions
- Sponsors & Donors
- Civil Society Organisations
- Researchers
- Media, Health & Science Writers
- Informed Citizens

#### Issue / News

- Coming Soon
- HRWeb License

**Idea Box**

#### Powered By

**Council on Health Research for Development (COHRED)**

# HRWeb (2)

## navigation

- Main Page
- A growing resource
- HRWeb Governance
- Milestones
- Supporters
- Help
- COHRED

## region and countries

- World map
- Select a country

## toolbox

- How to get started?
- User Guide
- How can you contribute?
- Priority Setting
- HRWeb RSS
- Country Background
- Country Reviewers
- Contact us

page

## Tanzania

- › Governance and Policies
- › National Priorities for Health Research
- › Key Institutions / Networks
- › Ethics Review of Health Research
- › Research Financing and Partnerships
- › Health Research Projects and Publications
- › Information Resources

 [RSS - Tanzania | What is RSS?](#)



- ★ Capital City
- ★ Regional Capital City
- Significant City
- Important City - Town
- Attraction - Landmark
- River
- ▲ Highest Point

 [Log in / Create an account](#) - English



POWERED BY COHRED BETA

navigation

- Main Page
- A growing resource
- HRWeb Governance
- Milestones
- Supporters
- COHRED

region and countries

- World map
- Select a country

toolbox

- How to get started?
- User Guide
- How can you

page

Log in / Create an account - English

Search

# Tunisia

- » Governance and Policies
- » National Priorities for Health Research
- » Key Institutions / Networks
- » Regulation and Ethics Review of Research
- » Research Financing and Partnerships
- » Health Research Projects and Publications

## Information Resources

RSS - Tunisia | What is RSS?



- ★ Capital City
- ★ Regional Capital City
- Significant City
- Important City - Town
- Attraction - Landmark
- River
- ▲ Highest Point

## Information Resources

[ Discussion ] [ Edit ] [ History ]

# South Africa

- › Governance and Policies
- › National Priorities for Health Research
- › Key Institutions / Networks
- › Ethics Review of Health Research
- › Research Financing and Partnerships
- › Health Research Projects and Publications
- › Information Resources



★ Capital City   ★ Regional Capital City  
 ● Significant City   ● Important City - Town  
 □ Attraction - Landmark   □ River   ▲ Highest Point

RSS - South Africa | What is RSS?

Navigation

- Main Page
- A growing resource
- HRWeb Governance
- Milestones
- Supporters
- Help
- COHRED

Region and countries

- World map
- Select a country ▼

toolbox

- How to get started?
- User Guide
- How can you contribute?
- Priority Setting
- HRWeb RSS
- Country Background
- Country Reviewers
- Contact us

## Ethics Committees - Ethics Documents - Map - Brief

[\[ Submission form \]](#) [\[ Discussion \]](#) [\[ History \]](#)

REC/IRB Name	Institution Name	Other Specifications	Type	URL	More details
Pharma-Ethics Independent Research Ethics Committee	Pharma-Ethics Independent Research Ethics Committee		Private	<a href="http://www.pharma-ethics.co.za">www.pharma-ethics.co.za</a>	
Tshwane University of Technology Research Ethics Committee	Tshwane University of Technology		Institutional	<a href="http://www.tut.ac.za/Other/RnI/ethics/Pages/default.aspx">http://www.tut.ac.za/Other/RnI/ethics/Pages/default.aspx</a>	
Health and Wellness Sciences Research Ethics Committee	Health and Wellness Sciences Research Ethics Committee		Other	<a href="http://www.cput.ac.za/researchdirectorater/committees.php">http://www.cput.ac.za/researchdirectorater/committees.php</a>	

Disclaimer:

The entries on this page are provided by the ethics committees. The initial data was migrated from HRWeb phase I. COHRED staff may continue to post public documents on this page until the agreement with the ethics committees is concluded. This will be clearly indicated in the history log for this page.

navigation

- Main Page
- A growing resource
- HRWeb Governance
- Milestones
- Supporters
- Help
- COHRED

region and countries

- World map
- Select a country

toolbox

- How to get started?
- User Guide
- How can you contribute?
- Priority Setting
- HRWeb RSS
- Country Background
- Country Reviewers
- Contact us

# South Africa

- › Governance and Policies
- › National Priorities for Health Research
- › Key Institutions / Networks
- › Ethics Review of Health Research
- › Research Financing and Partnerships
- › Health Research Projects and Publications
- › Information Resources

RSS - South Africa | What is RSS?



★ Capital City   ★ Regional Capital City  
 ● Significant City   ● Important City - Town  
 □ Attraction - Landmark   □ River   ▲ Highest Point

## Tshwane University of Technology

[\[ Back to Ethics Review \]](#) [\[ Discussion \]](#)

Tshwane University of Technology Research Ethics Committee

Institutional

University

Chairperson: Dr. WA Hoffmann

Chairperson e-mail: hoffmannwa@tut.ac.za

REC/IRB administrator's name: Dr. WA Hoffmann

REC/IRB administrator's e-mail: hoffmannwa@tut.ac.za

Alternative email addresses: baileyg@tut.ac.za

REC/IRB telephone: 27 12 382 6265

URL: <http://www.tut.ac.za/Other/Rnl/ethics/Pages/default.aspx>

### Physical address:

Directorate Research, Innovation and Partnerships Tshwane University of Technology

Staatsartillerie Road Pretoria West 0183

### Postal address:

Directorate Research, Innovation and Partnerships Tshwane University of Technology Private

Bag X680 Pretoria 0001

### Preferred manner to receive protocols:

Email

### Operational language(s) of the committee:

English

### How often does your REC convene to consider study protocols?

monthly

### How long in advance should the protocol be submitted:

2 months

### Timetable:

The 3rd or 4th Monday of the month

### Link(s) to the REC/IRB's:

Electronic documents available on request

# MARC (5)

- Extended partnerships for MARC / *HRWeb* in ethics & drug regulation –
  - EDCTP ([www.edctp.org](http://www.edctp.org))
  - AVAREF ([www.who.int](http://www.who.int))
  - TRREE ([www.elearning.trree.org](http://www.elearning.trree.org))
  - other: *beyond ethics, even beyond health*
    - Senegal – Ministry of Health
    - WAHO (15 countries)
    - EMRO
    - PAHO
    - Tanzania (COSTECH)
    - NEPAD S&T (19 countries +)

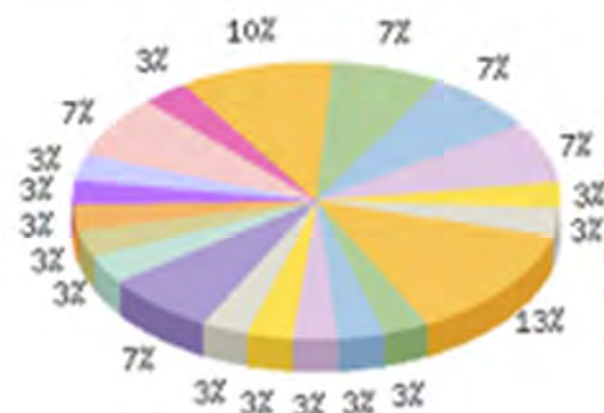


# progress (1)

- MARC mapping –
  - start with ethics review committee info
  - 3-step information collection
    - 1<sup>st</sup>: basic contact and procedural info – MARC will do
    - 2<sup>nd</sup>: extended capacity info / standardized – RECs will do
    - 3<sup>rd</sup>: extended info / optional - RECs may do
  - level 1 information (as at 1 October 2009)
    - on (91) committees
    - in (27) countries (some in Latin America)

## REC Contact Update Aggregate View

### 1.1. Country



Botswana (4)

Madagascar (1)

Burkina-Faso (1)

Namibia (1)

Cameroon (1)

Nigeria (2)

Congo (DRC) (1)

Senegal (1)

Egypt (1)

South Africa (3)

Ethiopia (1)  
Sudan (2)

Ghana (2)

Tanzania (2)

Kenya (1)

Uganda (2)

Liberia (1)

Zambia (1)

Libya (1)

Zimbabwe (1)

# progress (3)

- MARC mapping –
  - Currently 91 committees in over 27 countries
  - Submission form for REC to enter three levels of information:
    - Level 1: Basic contact and procedural information
    - Level 2: Capacity and facilities
    - Level 3: any information that RECs want to make known
  - forms for RECs and *HRWeb* agreements ready
  - participants are keen for on-line registration
  - contacts with drug regulation made

# some lessons learned...

- ‘ownership’ of information
  - *more important than its use ?*
- ‘on-line’ registration vs telephone support
  - *great preference for self-registration*
- useable information on ethics review and drug regulatory authorities is scarce
  - *HRWeb key platform to develop both and likely to enhance efficiency of both*
- visibility of information has advantages
  - creates ‘positive peer pressure’

# immediate next steps (1)

- motivating RECs to enter 'stage 2' data
  - detailed capacity information
- Getting RECs to use the platform to improve own functioning
- start with ethics review capacity building programme mapping – and provide analyses
- develop 'drug regulatory authority' pages
  - link to TRREE, WHO, NEPAD, AVAREF

# immediate next steps (2)

- encourage use of HRWeb / HRWeb (Ethics)
  - arrangements with different user groups will assist understanding nature of the platform
    - donors / research sponsors
    - governments
    - research institutions
    - civil society
    - media
  - enhance functionality of HRWeb
    - networking function
    - your own inputs ...
    - ‘third party programming’ (see next slide)

**Service d'Epidémiologie**  
**CHU Farhat Hached Sousse Tunisie**


Service d'Epidémiologie  
 Unité de veille documentaire  
 Accès aux publications  
 Infos service

Chercher Recherche avancée

- Accueil
- Service
- Activités
- Publications
- Unités de recherche
- Contact

**Accès rapide**

- Accès par spécialité
- Accès par auteur
- Accès par zone de faculté
- Accès par revue
- Accès par institution



**Dernières nouvelles**

28 Septembre 2009  
 Programme de formation continue année 2009-2010 en Méthodologie (Voir tableau récapitulatif dans la rubrique infos Service).

**Répertoire des publications**

**Recherche avancée**

Pour effectuer une recherche avancée, vous devez spécifier vos critères de choix pour les résultats à afficher.

Mot clé :

# MARC and you ... (1)

- researchers
  - more transparent and efficient ethics review
  - and drug regulatory mechanisms
- donors
  - can better target support for ethics capacity building
- RECs
  - free ethics review management system
- research sponsors
  - ‘one-stop shop’ for ethics review, drug regulation, project registry, link to clinical trial registries



# MARC and you ... (2)

- MARC and *HRWeb*/Ethics only as good as its user base and contributions. It is a 'living' resource
  - ... get online
  - ... make suggestions
  - ... adapt it, or have it adapted
- and let us know how it can be even more functional

# EAN

# News

*Newsletter of the EPIET  
Alumni Network*



September 2009

## EPI Tools

Health research as a development tool:  
introducing *HRWeb*

*By Lorenzo Pezzoli (Cohort 12, EAN Board) and  
David Abreu (COHRED)*

It surely happened to many of us when drafting a study protocol, to search for information about ongoing projects and their results in the country of interest. Who is doing what in which country? What is the main research need in this country? What has been done so far? Have the results been published? Who to contact if I need funding for my project? With whom should I collaborate to optimize the research? And so on... In most of the cases this information is already floating in the Internet Ocean, but it takes many sleepless nights to “surf” it all, with the risk of missing some key aspect anyway.

With the risk of sounding like a movie trailer: Imagine a World where all these important questions could be answered with just a couple of clicks! With this in mind COHRED has designed the Health Research Web (<http://www.healthresearchweb.org/>) or *HRWeb*, as a global forum to share all relevant information on health research by country.

COHRED – Council on Health Research and Development



### EPI Tools

Health research as a development tool: introducing *HRWeb*

By Lorenzo Pezzoli (Cohort 12, EAN Board) and David Abreu (COHRED)

Looking forward to meeting soon -  
on *HRWeb*

*Health Research Web:*  
[www.healthresearchweb.org](http://www.healthresearchweb.org)

COHRED: [www.cohred.org](http://www.cohred.org)

SARETI: <http://shsph.up.ac.za/sareti.html>