



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

CAREL IJSSELMUIDEN, DEBBIE MARAIS, DOUGLAS WASSENAAR AND BOITUMELO MOKGATLA-MOIPOLAI

## Keywords

Africa,  
 Research Ethics Committee,  
 capacity,  
 HRWeb,  
 MARC,  
 mapping

## ABSTRACT

Health research initiatives worldwide are growing in scope and complexity, particularly as they move into the developing world. Expanding health research activity in low- and middle-income countries has resulted in a commensurate rise in the need for sound ethical review structures and functions in the form of Research Ethics Committees (RECs). Yet these seem to be lagging behind as a result of the enormous challenges facing these countries, including poor resource availability and lack of capacity. There is thus an urgent need for ongoing capacity and resource development in these regions in general, and in Africa in particular. Similarly, there is a need for research and initiatives that can identify existing capacity and funding and indicate the areas where this needs to be developed.

This discussion paper argues that the Mapping African Research Ethics Capacity (MARC) project is a timely initiative aimed at identifying existing capacity. MARC provides a platform and tool on the Council on Health Research for Development's (COHRED) Health Research website (HRWeb), which can be used by RECs and key stakeholders in health research in Africa to identify capacity, constraints and development needs. MARC intends to provide the first comprehensive interactive database of RECs in Africa, which will allow for the identification of key relationships and analyses of capacity. The potential of MARC lies in the mapping of current ethical review activity onto capacity needs. This paper serves as a starting point by providing a descriptive illustration of the current state of RECs in Africa.

## INTRODUCTION

Health research initiatives, which are growing in both quantity and complexity globally, play a key role in improving health and development of low-income and middle-income countries. Several initiatives have contributed significantly to capacity strengthening of health research in sub-Saharan Africa, including those supported by the World Health Organization (WHO) and Tropical Disease Research (TDR), the Swedish International Development Agency (SIDA) and Department for Research Cooperation (SAREC), the European Union,

the Bill & Melinda Gates Foundation, the International Clinical Epidemiology Network (INCLIN), the Fogarty International Center of the US National Institutes of Health (NIH) and the Wellcome Trust,<sup>1</sup> many individual institutional collaborative studies and, over the past few years, the private (pharmaceutical) sector.<sup>2</sup>

<sup>1</sup> J.A.G. Whitworth et al. Strengthening Capacity for Health Research in Africa. *Lancet* 2008; 372: 1590–1593.

<sup>2</sup> C.A. Gardner, T. Acharya & D. Yach. Technological and Social Innovation: A Unifying New Paradigm for Global Health. *Health Aff* 2007; 4: 1052–1061; C. M. Morel et al. Health Innovation Networks to Help Developing Countries Address Neglected Diseases. *Science* 2005;

Address for correspondence: Debbie Marais, COHRED – R&D, University of KwaZulu-Natal, P/Bag X01, Scottsville 3209, Pietermaritzburg, South Africa. Email: marais@cohred.org.

Conflict of interest statement: No conflicts declared

In addition, research sponsors are conducting more of their studies in low and middle-income countries,<sup>3</sup> for a number of reasons: because it is or is assumed to be less expensive,<sup>4</sup> because it has become increasingly difficult to find a sufficient number of qualified participants in the sponsors' home countries,<sup>5</sup> and because funders are responding to the need for research into questions pertinent to the African context. Nonetheless, there is evidence that over 90% of all external funding for research in Africa goes to three conditions: HIV/AIDS, malaria and tuberculosis;<sup>6</sup> many other conditions and diseases still fall through the cracks and become neglected.

The potential for exploitation in such circumstances has been highlighted by some highly publicised violations of international ethical codes in the developing world,<sup>7</sup> which in turn has led to increased awareness about the need for improved ethics oversight of health research in developing countries.<sup>8</sup> Regarding more recent HIV vaccine studies (STEP and Phambili), there was much

scientific response in the literature,<sup>9</sup> but no strong ethical critiques were published in peer-reviewed journals that we are aware of, other than a commentary by Macklin.<sup>10</sup>

It is widely acknowledged that REC review of health research protocols is a cornerstone of international guidelines on research with human participants.<sup>11</sup> In recent years, many low- and middle- income countries have begun to pay greater attention to developing or strengthening RECs, with a number of research institutions in resource-poor countries establishing RECs on their own initiative, even in the absence of governmental mandates.<sup>12</sup> The ever-increasing activity in health research involving human participants in developing countries has resulted in a commensurate rise in the need for sound ethical review structures and functions within these countries.

The importance of regulatory and ethical review authorities in developing countries being able to demonstrate capacity in competent ethical review and oversight cannot be over-emphasised. Where local or national efforts are hindered by resource constraints, many countries are now taking up the challenge and investing significant resources to strengthen the capacity of RECs to review proposed human participants' research. Implicit in these efforts is the assumption that REC review will result in research that better complies with applicable ethical principles and, therefore, afford greater protection to those who participate in such research.<sup>13</sup>

However:

while many other areas and capacities continue to benefit and improve from the inflow of health research funding into Africa, the core oversight structures such as research ethics committees seem to be lagging behind. This is mainly because, in Africa, where most governments are faced with many other competing socioeconomic challenges, such frameworks have remained underfunded.<sup>14</sup>

Consequently, enormous challenges remain for sub-Saharan Africa to establish a common framework for sustainable research ethics review capacity.<sup>15</sup>

309: 401–404; S. Nwaka & R.G. Ridley. Virtual Drug Discovery and Development for Neglected Diseases Through Public–Private Partnerships. *Nat Rev Drug Discov* 2003; 2: 919–928.

<sup>3</sup> S.W. Glickman et al. Ethical and Scientific Implications of the Globalization of Clinical Research. *N Engl J Med* 2009; 360: 816–822; G. Koski & S.L. Nightingale. Research Involving Human Subjects in Developing Countries. *N Engl J Med* 2001; 345: 136–138; S. Shah. Globalization of Clinical Research by the Pharmaceutical Industry. *Int J Health Serv* 2003; 33: 29–36; F.A. Thiers, A.J. Sinskey & E. R. Berndt. Trends in the Globalization of Clinical Trials. *Nat Rev Drug Discov* 2008; 7: 13–14.

<sup>4</sup> F. Kelleher. The Pharmaceutical Industry's Responsibility for Protecting Human Subjects of Clinical Trials in Developing Nations. *Colum J L & Soc Probs* 2004–2005; 38: 67–106; A. Petryna. Ethical Variability: Drug Development and Globalizing Clinical Trials. *Am Ethnol* 2005; 32: 183–197.

<sup>5</sup> Kelleher, *op. cit.* note 4; J. McGregor. Does the Use of Human Subjects in Research in Developing Nations Violate Their Human Rights? If So, Are Reparations an Appropriate Response? *J Soc Philos* 2006; 37: 441–463.

<sup>6</sup> Council on Health Research for Development (COHRED). 2007. COHRED Statement on Responsible Vertical Programming: How Global Health Research can Deliver Essential Research, Achieve Impact and Build National Systems. Geneva, Switzerland: COHRED; M. Moran et al. 2009. G-Finder Report 2009: Neglected Disease Research & Development: New Times, New Trends. Sydney, Australia: Health Policy Division George Institute for International Health.

<sup>7</sup> S.M. Angell. The Ethics of Clinical Research in the Third World. *NEJM* 1997; 337: 847–849; C.H. Coleman & M.C. Bouësseau. How Do We Know that Research Ethics Committees Are Really Working? The Neglected Role of Outcomes Assessment in Research Ethics Review. *BMC Med Ethics* 2008; 9: doi:10.1186/1472-6939-9-6; P. Lurie & S. Wolfe. Unethical Trials of Interventions to Reproduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries. *NEJM* 1997; 337: 853–856; H. Varmus & D. Satcher. Ethical Complexities of Conducting Research in Developing Countries. *NEJM* 1997; 337: 1003–1005.

<sup>8</sup> S. Chima. Regulation of Biomedical Research in Africa. *BMJ* 2006; 332: 848–851; R.A. Noor. Health Research Oversight in Africa. *Acta Trop* 2009; 112S: S63–S70.

<sup>9</sup> J.P. Moore et al. K. A STEP into Darkness or Light? *Science* 2008; 320: 753–755.

<sup>10</sup> R. Macklin. Ethics in Preventive HIV Research. *HIV Ther.* 2009; 3: 229–236.

<sup>11</sup> S.S. Bhat & T.T. Hegde. Ethical International Research on Human Subjects Research in the Absence of Local Institutional Review Boards. *J Med Ethics* 2006; 32: 535–536; J. Parvizi et al. Institutional Review Board Approval: Why It Matters. *J Bone Joint Surg* 2007; 89: 418–426; A. Slowther, P. Boynton & S. Shaw. Research Governance: Ethical Issues. *J R Soc Med* 2006; 99: 65–72.

<sup>12</sup> Coleman & Bouësseau, *op. cit.* note 7.

<sup>13</sup> *Ibid.*

<sup>14</sup> Noor, *op. cit.* note 8, p. 564.

<sup>15</sup> Whitworth et al. *op. cit.* note 1.

## LITERATURE REVIEW

### REC capacity in developing countries: Constraints

In Africa, where wide social disparities and weak health care systems exist,<sup>16</sup> major concerns over research ethics committee operations remain. Ethical review and subsequent monitoring of health research require adequate resources and expertise – capacities which are limited in various ways in most African research ethics committees. These RECs are typically required to interpret international ethics guidelines in complex socioeconomic and cultural environments, which in turn are often characterised by power inequalities and economic disparities.<sup>17</sup> Although the majority of countries in Africa are reported to have at least some form of ethical review process in place,<sup>18</sup> in many cases these processes are fraught with challenges, including poor financial and human resources, insufficient training and inadequate standard operating procedures.<sup>19</sup> For the most part, REC capacity in low-middle income countries continues to be hampered by lack of capacity, in both practical and conceptual terms.

Given the growing volume and complexity of health research in Africa,<sup>20</sup> several empirical studies have highlighted the need for ongoing research ethics capacity development on the continent.<sup>21</sup> Some of the major challenges facing RECs in a number of African countries were identified in these studies as inadequate training and expertise, insufficient representation by discipline, gender

and age, inconsistent funding and budget constraints, inadequate resources (including lack of office equipment and outdated or lack of standard operating procedures), lack of electronic data management systems, multiple responsibilities of REC members, poor recognition of the importance of the role of the committees, and the questionable independence of RECs which appeared to ‘rubber stamp’ approvals in order to secure international funding.<sup>22</sup>

### Initiatives undertaken to strengthen REC capacity

Emerging and innovative technologies create additional challenges for these RECs in their efforts to provide efficient reviews and the oversight required for health research in Africa. This not only affects the credibility of these RECs in processing reviews and approvals, but it also significantly weakens their ability to provide quality health research oversight. There is thus a need for tools to facilitate the administration of these committees and to enable them to streamline their protocol review procedures.

Current strategies to optimise REC review and oversight in Africa are mainly done by a handful of not-for-profit African and international organisations.<sup>23</sup> Initiatives aimed specifically at increasing capacity for ethical review of health research in Africa include funding from the WHO-UNAIDS African AIDS Vaccine Programme (AAVP); the African Malaria Network Trust (AMANET); the National Institutes of Health’s (NIH) Fogarty International Center’s South African Research Ethics Training Initiative (SARETI); the International Research Ethics Network for Southern Africa (IRENSA); the West African Bioethics Initiative (WAB); the Wellcome Trust; the European Union (EU); the Global Bioethics Forum; the World Health Organization (WHO), and the EU European Developing Countries Clinical Trials Partnership (EDCTP) which partially funds, for example, a high-level online capacity building programme known as TRREE.<sup>24</sup>

Capacity building efforts such as those mentioned above have been instrumental in providing basic ethical infrastructure in Africa. Despite substantial investment

<sup>16</sup> L. London. Ethical Oversight of Public Health Research: Can Rules and IRBs Make a Difference in Developing Countries. *Am J Public Health* 2002; 92: 1884–1885.

<sup>17</sup> C. Milford, D. Wassenaar & C. Slack. Resources and Needs of Research Ethics Committees in Africa: Preparations for HIV Vaccine Trials. *IRB* 2006; 28: 2–9.

<sup>18</sup> J. Kirigia, C. Wambebe & A. Baba-Moussa. Status of National Research Bioethics Committees in the WHO Africa Region. *BMC Med Ethics* 2005; 6: 10–16.

<sup>19</sup> Coleman & Bouësseau, *op. cit.* note 7; P. Effa, A. Massougbojji & F. Ntoumi. Ethics Committees in Western and Central Africa: Concrete Foundation. *Dev World Bioeth* 2007; 7: 136–142; A. Nyika et al. Composition, Training Needs and Independence of Ethics Review Committees across Africa: Are the Gate Keepers Rising to the Emerging Challenges? *J Med Ethics* 2009; 35: 189–193.

<sup>20</sup> Glickman et al. *op. cit.* note 3; Koski & Nightingale, *op. cit.* note 3; D. Maïga, B.D. Akanmori & L. Chocarro. Regulatory Oversight of Clinical Trials in Africa: Progress Over the Past 5 Years. *Vaccine* 2009; 27: 7249–7252.

<sup>21</sup> J. Ikingura, M. Kruger & W. Zeleke. Health Research Ethics Review and Needs of Institutional Ethics Committees in Tanzania. *Tanzan Health Res Bull* 2007; 9: 154–158; N. Kass et al. The Structure and Function of Research Ethics Committees in Africa: A Case Study. *PLoS Med* 2007; 4: e03, doi:10.1371/journal.pmed.0040003; Kirigia et al. *op. cit.* note 18; Milford et al. *op. cit.* note 17; A. Nyika et al. Capacity Building of Ethics Review Committees Across Africa Based on the Results of a Comprehensive Needs Assessment Survey. *Dev World Bioeth* 2008; doi:10.1111/j.14718847.2008.00243.x.

<sup>22</sup> J. Ateudjieu et al. Training Needs Assessment in Research Ethics Evaluation Among Research Ethics Committee Members in Three African Countries: Cameroon, Mali and Tanzania. *Dev World Bioeth* 2009; doi: 10.1111/j.1471-8847.2009.00266.x; Ikingura et al. *op. cit.* note 21; Kass et al. *op. cit.* note 21; Nyika et al. *op. cit.* note 21; J.P. Rwabihama, C. Girre & A.M. Duguet. Ethics Committees for Biomedical Research in Some African Emerging Countries: Which Establishment for which Independence? A Comparison with the USA and Canada. *J Med Ethics* 2010; 36: 243–249.

<sup>23</sup> *Ibid.*

<sup>24</sup> Milford et al. *op. cit.* note 17.

The South African Research Ethics Training Initiative (**SARETI**): Based at the Universities of KwaZulu-Natal and Pretoria, SARETI provides training in research ethics to African researchers and REC members. To date, SARETI has trained 37 students across Africa ([www.shpsh.up.ac.za/sareti](http://www.shpsh.up.ac.za/sareti))

The International Research Ethics Network for Southern Africa (**IRENSA**): Based at the University of Cape Town, IRENSA provides short term training for mid-career African students and REC members. 82 students within Southern Africa have been trained to date ([www.irensa.org](http://www.irensa.org))

**AMANET** Research Ethics Capacity Strengthen Grant: Supported by the Gates Foundation, AMANET provides capacity building programmes aimed at identifying specific gaps in the ethical review process in Africa. 32 RECs have benefited from this grant thus far ([www.amanet-trust.org](http://www.amanet-trust.org))

Middle East Research Ethics Training Initiative (**MERETI**): Offers a 12-month certificate programme in research ethics and has trained 41 people in the Middle East ([www.mereti.net](http://www.mereti.net))

Fogarty African Bioethics Training Program (**FABTP**): Offers capacity development partnership in research ethics for institutions within Africa. So far, 30 students across Africa have been trained through this programme ([www.bioethicsinstitute.org](http://www.bioethicsinstitute.org)).

West African Bioethics Training Program: Based at the University of Ibadan, Nigeria, this programme offers postgraduate degree training in bioethics ([www.westafricanbioethics.net](http://www.westafricanbioethics.net))

Figure 1. Summary of Capacity Building Training Initiatives in Africa.<sup>25</sup>

in research ethics capacity development through generous training programmes grants over the past 10–12 years (see Figure 1 above and Appendix 1 of this paper), sustainability of these efforts is crucial for enhanced and continued health research oversight in Africa.

### Where gaps remain: Need for continued investment & collaborative efforts

The paucity of resources for ethical review process in Africa and the need to strengthen the process through various training programmes make it critical for the organisations working in this field to streamline their activities and programmes and promote synergistic collaborative efforts.<sup>26</sup>

Successful implementation of ethical guidelines and principles depends heavily on existing frameworks for health research oversight. In the developing world, however,

<sup>25</sup> Note that the training referred to here is training provided by SARETI, IRENSA, MERETI and the JHU Bioethics Programme. This is by no means a comprehensive picture of available training, including short courses and workshops, in research ethics occurring in Africa. However, these programmes arguably provide approximately 80% of the formal, longer-term substantive training in research ethics in Africa. See Appendix 1 of this paper for further details.

<sup>26</sup> Nyika et al. *op. cit.* note 19, p. 190.

such frameworks are often either nonexistent or rudimentarily formed,<sup>27</sup> with a handful of notable exceptions on the African continent.<sup>28</sup>

Recent papers argue clearly that RECs need to be more aware of promoting capacity development,<sup>29</sup> and ensuring that research aligns with local health policy and development agendas.<sup>30</sup> Furthermore, some critics suggest that,<sup>31</sup> despite investment by foreign donors, ethics review of controversial studies,<sup>32</sup> in Africa, remains inadequate. Research ethics training requires ongoing effort, even for those who have been trained,<sup>33</sup> as the research ethics agenda changes with regional development and health objectives and the growing complexity of research, clinical trial designs<sup>34</sup> and globalised clinical trials<sup>35</sup> in developing countries.<sup>36</sup>

Such capacity building efforts need to move beyond their current focus (training, infrastructural upgrades, standard operating procedures (SoPs) and administrative systems) and should focus on harmonising their procedures and improving information sharing among and between ethics committees and regulatory authorities.<sup>37</sup> In particular, there is a need for:

[s]tudies that explore the cost and benefits (effectiveness) of alternative ways of leveraging the recent advances in technology (teleconferencing, video conferencing, internet and email) to boost the [capacity and] efficiency of RECs. Where these technologies

<sup>27</sup> Chima, *op. cit.* note 8.

<sup>28</sup> P. Cleaton-Jones & D. Wassenaar. Protection of Human Participants in Health Research – A Comparison of Some US Federal Regulations and South African Research Ethics Guidelines. *S Afr Med J* 2010; 100: 710–716; Noor, *op. cit.* note 8.

<sup>29</sup> C.B. IJsselmuiden et al. Evolving Values in Ethics and Global Health Research. *Glob Public Health* 2010; 5: 154–163.

<sup>30</sup> S. Abdool Karim & Q.A. Abdool Karim. AIDS Research Must Link to Local Policy. *Nature* 2010; 463: 733–734; N. Sewankambo & C. IJsselmuiden. Responsive Research in Developing Countries. *Lancet* 2008; 372: 11–13.

<sup>31</sup> S. Philpott & U. Schüklenk. A Study that Should Not Have Been Done. *Hastings Center Forum* 2010; Available at: <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4626> [Accessed 21 Dec 2010].

<sup>32</sup> S. Abdool Karim et al. Timing of Antiretroviral Drugs During Tuberculosis Therapy. *N Engl J Med* 2010; 362: 607–706.

<sup>33</sup> Rwabihama et al. *op. cit.* note 22.

<sup>34</sup> H.M.J. Hung et al. A Regulatory View on Adaptive/Flexible Clinical Trial Design. *Biom J* 2006; 48: 565–573.

<sup>35</sup> G.J. Annas. Globalized Clinical Trials and Informed Consent. *N Engl J Med* 2009; 360: 2050–2053; Glickman et al., *op. cit.* note 3; D. Normille. The Promise and Pitfalls of Clinical Trials Overseas. *Science* 2008; 322: 214–216; Thiers et al., *op. cit.* note 3.

<sup>36</sup> A.A. Hyder, L. Dawson, A.M. Bachani & J.V. Moving from Research Ethics Review to Research Ethics Systems in Low-Income and Middle-Income Countries. *Lancet* 2009; 373: 862–865; C. Lorenzo, V. Garrafa, J.H. Solbakk & S. Vidal. Hidden Risks Associated with Clinical Trials in Developing Countries. *J Med Ethics* 2010; 36: 111–115.

<sup>37</sup> Noor, *op. cit.* note 8.

exist, they would not only reduce the cost of face-to-face meetings but will also ensure timely review of research protocols . . . Thus, there is an urgent need for research into finding innovative mechanisms for ethically financing and supporting REC activities.<sup>38</sup>

Against this background, the Mapping African Research Ethics Capacity (MARC) project is a timely initiative aimed at identifying existing capacity, providing a platform or tool (on Health Research Web – *HRWeb*) which can be used by RECs in Africa to identify capacity constraints and development needs, and thus seek appropriate support to improve their ability to provide quality and comprehensive health research oversight. The Council on Health Research for Development's (COHRED) Health Research Web (*HRWeb*) platform is a 'semi-wiki' mechanism for hosting this initiative and for developing capacity and collaboration in ethical review for RECs in Africa.

### Background to the Mapping African Research Ethics Capacity (MARC) initiative

In 2009, the European and Developing Countries Clinical Trials Partnership (EDCTP) made funding available for the establishment of the MARC project. MARC is a three-year project that aims to map online health research ethics and regulatory activities in Africa – essentially in support of EDCTP-funded clinical trial sites and projects, but with wider applicability. The partners in the MARC project are the EDCTP, COHRED and the University of KwaZulu-Natal (UKZN) – in particular, the South African Research Ethics Training Initiative (SARETI), located in the School of Psychology at UKZN in Pietermaritzburg, South Africa.

There are three components to the MARC project: 1) the online mapping of research ethics committees, 2) building capacity in research ethics in Africa, and 3) the mapping of medicines regulatory authorities in Africa. This paper reports only on the first of these three objectives.

Because the EDCTP commits substantial funding to clinical trials and clinical trials capacity in African countries, it is logical that it should invest resources in providing an up-to-date overview of ethics and clinical trial related regulatory activity that is inclusive of capacity assessment and capacity building assessment. Ideally, such ethics review capacity mapping should:

- Link to general research and health research system information;
- Be ongoing and self-updating, rather than *ad hoc* and static;

- Allow mapping of other ethics review and clinical trials capacity building initiatives; and
- Form a basis for capacity enhancement through the presentation and analysis of its data.

MARC's ultimate goal is to ensure that everyone who needs such information would be able to upload it or access it. Therefore, although EDCTP funding has enabled the development of MARC as an interactive resource, it is and will be globally available, so that RECs and others interested in research ethics review outside of Africa can use it.

### METHOD

Currently, no reliable, current information exists on ethics review capacity in Africa. Early efforts (by the WHO/UNAIDS African AIDS Vaccine Programme (AAVP ELH)) are now outdated, comprised of static contact information and membership, rather than information on capacity or ongoing capacity building needs and programmes.

The existing data available on the current capacity of RECs in the developing world, and in Africa in particular,<sup>39</sup> are mostly based on time-limited reviews, the results of which are typically out of date a year or so after publication. The MARC project aims to develop an interactive dynamic map of the capacity to ethically review health research in all African countries where the EDCTP operates. It links the ethics review capacity and ethics review capacity building initiatives to COHRED's *HRWeb*. While MARC is the EDCTP-funded project with the mandate to map REC data online, *HRWeb* is the platform on which this mapping is being done.<sup>40</sup>

Because REC capacity and activity ultimately involve more than just REC data, the benefit of the pairing of MARC with *HRWeb* is the potential for cross-linking the information that MARC gathers with other data related to health research that is available on *HRWeb*. This, in turn, will allow: ethics capacity analysis in relation to general health research system development and national health research priorities, encourage comparisons between countries inside and outside Africa, and facilitate sustainability and knowledge sharing throughout the project. In the future, it is envisaged that financial information on research for health will also be captured, enabling RECs to include research resourcing in their considerations.

<sup>39</sup> Ateudjieu et al. *op. cit.* note 22; Ikingura et al. *op. cit.* note 21; Kass et al. *op. cit.* note 21; Kirigia et al. *op. cit.* note 18; Milford et al. *op. cit.* note 17; Nyika et al. *op. cit.* note 19; Nyika et al. *op. cit.* note 21; Rwabihama et al. *op. cit.* note 22.

<sup>40</sup> For the purposes of this paper, MARC and *HRWeb*-ethics will be used interchangeably to refer to the online site on which REC data is being mapped.

<sup>38</sup> Kirigia et al. *op. cit.* note 18, p. 6.

Table 1. Format of REC Information Currently Available on HRWeb

BASIC LEVEL INFORMATION		
<b>Institutional Details</b>	Institution Name REC Name Type of REC	Institutional National Private
<b>Personnel Details</b>	Chairperson Name Administrator Name	
<b>Contact Details</b>	Address Telephone Email Fax URL	
<b>Protocol Procedures</b>	Operational Language Preferred manner of receiving protocols How often REC meets to review protocols How long in advance protocols need to be submitted Written documentation of submission & review procedures	
SECOND-LEVEL / ORGANISATIONAL INFORMATION		
<b>Member Details</b>	Number of Qualified Ethicists Number of Women Age Distribution Individual Member Details	Name Age Gender Speciality Highest Qualification Years on REC
<b>Term of Office</b>	Term of office for members of REC Is term of office renewable?	
<b>Training Requirements</b>	Do members require specific training in ethical review of research? How many members have had formal training?	
<b>Finances</b>	Does your REC have a dedicated budget? Are members remunerated for their work?	
<b>Facilities</b>	What facilities does your REC have?	Office Telephone Fax line Computer Internet connection Photocopier
<b>Administration</b>	Position of Administrator	Full-time Part-time None
<b>REC Procedures</b>	Does the REC have written operating procedures? Does the REC have written guidelines to assist researchers?	

More specifically, once the basic details of all identifiable African RECs have been entered onto MARC, more specific information on governance, policies, national priorities, financing and partnership, and other relevant documentation can also be uploaded and kept on the site. For RECs which already maintain an active website with this information, the site can simply provide increased exposure and be used as a means to direct researchers and other interested parties to the primary website. For RECs without an established website, MARC can host a virtual website for them, and can be a place where interested parties can find out more about that particular REC.

Besides being a useful source of information regarding specific REC documentation and protocols, and providing free web-based exposure, the MARC site will be a valuable tool for RECs to assess and review targets and

progress within their own committees. Furthermore, exposing RECs to neighbouring committees' SoPs and policies should enable and foster harmonisation and communication between RECs. This in turn will encourage renewed dialogue and exchange on current ethical review in Africa. The MARC site has numerous benefits for researchers, donors and RECs, and will grow and evolve in response to the needs of these groups.

Table 1 indicates the kind of information that is currently being requested from research ethics committees and uploaded onto MARC.

### Using a wiki approach

The first wiki software, WikiWikiWeb, was described by its developer as 'the simplest online database that could

possibly work.<sup>41</sup> Wiki is a Hawaiian word meaning quick or fast, which captures MARC's interactive, self-updating goal, making it ideal for use as a platform for achieving MARC's and *HRWeb*'s objectives. Wikis have emerged as highly collaborative, flexible and user-friendly tools for accessing and sharing knowledge on the internet, between individuals and between and within institutions.<sup>42</sup>

The MARC site, supported by *HRWeb*, uses a wiki-type approach that enables interactive and self-updating networking and knowledge sharing in real time. It is labelled as semi-wiki, because some parts of the site can only be uploaded or changed by 'owners' of this information. For example, RECs can upload their information about frequency of review. This information cannot be changed by other users – but anyone disagreeing with this information can enter changes in the discussion pages to make an impact over time. As a result of this approach, MARC has captured more information about the number and characteristics of RECs in Africa to date than any known alternative initiative or listing. For those critical of the wiki-type open-access model of data collection used by MARC, it should be pointed out that in the peer-reviewed published surveys of African REC capacity mentioned in our review above,<sup>43</sup> few located more than 30 RECs compared to the 98 currently listed on MARC.<sup>44</sup> In its relatively short existence, MARC, through *HRWeb*-ethics, has already increased its yield with respect to REC data on the African continent, both in number and scope of information gathered.

### Methodological advantages

In the classic knowledge quality-control environment, expert review committees conventionally decide what knowledge is valid and what knowledge is not. In the wiki environment, the domain is opened up – the quality of data is dependent, not on expert opinion, but on how many people access it and use it. How much the data is used in itself improves the quality of the information and data.

<sup>41</sup> W. Cunningham. 2002. *What is Wiki: WikiWikiWeb*. Available at: <http://www.wiki.org/wiki.cgi?WhatIsWiki> [Accessed 25 Nov 2010].

<sup>42</sup> H-J. Happel. Social Search and Need-Driven Knowledge Sharing in Wikis with Woogole. *WikiSym 2009: Proceedings of the 5th International Symposium on Wikis and Open Collaboration*. Available at: <http://www.wikisym.org/ws2009/proceedings/p99.pdf> [Accessed 25 Nov 2010].

<sup>43</sup> Ateudjieu et al. *op. cit.* note 22; Ikingura et al. *op. cit.* note 21; Kass et al. *op. cit.* note 21; Kirigia et al. *op. cit.* note 18; Milford et al. *op. cit.* note 17; Nyika et al. *op. cit.* note 19; Nyika et al. *op. cit.* note 21; Rwabihama et al. *op. cit.* note 22.

<sup>44</sup> 98 RECs were listed by MARC on *HRWeb*-ethics at the time of analysis for this paper; at the time of submission, this number had increased to 103 RECs, with a further 68 identified for inviting to upload their details.

In addition, the power of the wiki approach lies in the opportunity it offers for online collaboration among a 'community of practice: a way of achieving collective applied learning with the expectation that over time expertise in a given subject area is developed and solutions to common issues and shared problems are found, posted and discussed.'<sup>45</sup> In addition to their sustainability, wikis have also been shown to offer benefits to making work and collaborative efforts easier,<sup>46</sup> benefits to helping an organisation improve its processes, and benefits to enhanced reputation.<sup>47</sup>

Importantly, the self-updating nature of the wiki approach allows for real-time analysis of REC data to illuminate current gaps that can be immediately identified and even addressed – and can continue to be revised and addressed as the data continues to evolve and be updated. Anyone can access the data – either in the form of pre-selected indicators and graphic displays for immediate printing, or by downloading the spreadsheet information to conduct further analyses.

### Methodological limitations

While the simplicity of the wiki approach has many advantages, this same simplicity is also acknowledged as a possible methodological limitation. There are questions of validity and reliability of the data collected in such an approach. Because the quality of the data depends on users, significant user commitment and engagement are required, particularly in the earliest phases of information entry. The success of the approach lies in its interactive and real-time nature; as such, the extent to which users access, modify and utilise the shared information will largely determine data quality. At this time, the main quality control mechanism for information on MARC and *HRWeb* in general are country-reviewers – nationals representing three different constituencies (academia and research, government and management, and NGO/CSO) who are prompted twice yearly to review their own country pages and send in comments for changes. *HRWeb* works closely with these country-reviewers to establish the validity of uploaded data. Ultimately, however, MARC's wiki-approach means that it is the users of this platform who become the mechanism for

<sup>45</sup> R. Godwin-Jones. Blogs and Wikis: Environments for On-Line Collaboration. *Lang Learn Tech* 2003; 7: 12–16: 15.

<sup>46</sup> NIH / FIC has awarded SARETI/COHRED a grant to develop the 'social networking' or 'community of practice' function within *HRWeb*. It is currently online in a rudimentary manner, but will be fully functional by the end of 2011 – enabling, for example, RECs involved in the same multi-center trials to set up their own discussion group.

<sup>47</sup> A. Majchrzak, C. Wagner & D. Yates. Corporate Wiki Users: Results of a Survey. *WikiSym 2006: Proceedings of the 2006 International Symposium on Wikis*. Available at: <http://www.wikisym.org/ws2006/proceedings/p99.pdf> [Accessed 25 Nov 2010].

quality control – the more data that becomes available, the more it is subjected to public comment and review.

While quality control will remain an ongoing issue, the limitations of conventional published surveys of REC capacity to date, as mentioned above, should also be borne in mind. This problematises the issue of representativeness, which is key for establishing quality in epidemiological studies. Precisely because of the methodology employed in such studies, limited samples are typically accessed, resulting in compromised generalisability. The data gathered by MARC, it can be argued, has achieved greater representativeness, in that it has already surpassed existing survey data in terms of noting REC existence and capacity on the African continent.

## RESULTS

The process of collecting and recording current information on RECs operating in countries throughout Africa is ongoing. Since the initiation of MARC, snowball methods have been used to make initial and ongoing contact with various RECs throughout Africa and have almost doubled the MARC database of African RECs. At the time of writing, RECs in 25 African countries<sup>48</sup> have listed their basic level information on MARC, while a total of 98 RECs in Africa are currently listed on MARC.<sup>49</sup> We have identified a further 73 RECs that will be contacted, invited and supported to upload their details on the MARC site, bringing the working total to 171.

### Regional distribution of RECs

Regionally, the greatest number of RECs for which we have contact details are from Southern African countries (53), with 64.15% (34) of these currently listed on MARC. The Eastern and Western African regions both have a total of 41 RECs for which we have gathered information to date. However, only 34.15% (14) of these known RECs have uploaded information to MARC from the Eastern region, compared to 63.41% (26) of RECs on MARC from the West African region. Information has been obtained for 26 RECs from Northern Africa, of which 61.54% (16) are currently listed on MARC. Central Africa is the region with the lowest number of RECs (10),

<sup>48</sup> Algeria, Benin, Botswana, Burkina Faso, Cameroon, Cote d'Ivoire, Democratic Republic of Congo, Egypt, Ethiopia, Ghana, Kenya, Liberia, Libya, Madagascar, Mauritius, Namibia, Nigeria, Senegal, South Africa, Sudan, Tanzania, Tunisia, Uganda, Zambia, Zimbabwe.

<sup>49</sup> 98 RECs were listed by MARC on *HRWeb*-ethics at the time of analysis for this paper; at the time of submission, this number had increased to 103 RECs, with a further 68 identified for inviting to upload their details.



Figure 2. Geographical Distribution of RECs in Africa.

with 80% of these already listed on MARC. Figure 2 shows the distribution of RECs on the African continent.

The REC to population ratio discussed below is a rough indicator of capacity in a country.<sup>50</sup> In the absence of data on the number of RECs in relation to the number of research participants or studies in a country, the best rough proxy available at present is REC/population. MARC, through its host site *HRWeb*, will facilitate an analysis of number of RECs proportionate to research activity or number of clinical trials in each region. For now, available regional data allows for analysis of proportion of RECs to population by region, as well as an analysis of the number of people trained in research ethics proportionate to the number of RECs per region.

As shown in Table 2 below, the Southern African region has the greatest proportion of RECs to population (45.10), while the Central African region has the least RECs in proportion to population size (a proportion of 9.26). The greatest number of people who have received formal training<sup>51</sup> in research ethics appear to be from the

<sup>50</sup> The REC/population ratio is intended as a rough indicator of capacity in a country and clearly depends on the intensity of research going on. We acknowledge that an REC/population ratio is imperfect. A better index would be RECs per number of major studies, or even number of research participants. The MARC database with *HRWeb* might be able to generate such ratios in future.

<sup>51</sup> Note that the training referred to here is training provided by SARETI, IRENSA, WAB, MERETI and the JHU Bioethics



Table 2. Regional REC &amp; Training Information

Region	Total known RECs in region to date	Total RECs on HRWeb by region	Percentage of RECs on HRWeb of known total to date	Population by Region	Proportion of RECs to Population	Individuals Trained in Ethics by Region	Proportion of People Trained to RECs	Proportion of People Trained to Population
Northern	26	16	61.54	202228518	12.51	32	1.23	15.39
Southern	53	34	64.15	125904727	45.10	89	1.68	70.69
Western	41	26	63.41	291838350	14.05	23	0.56	7.88
Eastern	41	14	34.15	255332846	16.43	31	0.76	12.41
Central	10	8	80.00	107940341	9.26	4	0.40	3.70
<b>Totals</b>	171	98	57.31	983244782		179		

Table 3. REC &amp; Training Information by Language Region

Region	Total known RECs in region to date	Total RECs on HRWeb by region	Percentage of RECs on HRWeb of known total to date	Population by Region	Proportion of RECs to Population	Individuals Trained in Ethics by Region	Proportion of People Trained to RECs	Proportion of People Trained to Population
Francophone	28	19	67.86	253841791	11.03	6	0.21	2.36
Anglophone	110	59	53.64	387325929	28.40	136	1.24	35.11
Lusophone	1	0	0.00	36002535	2.78	0	0.00	0.00
Arabophone	32	20	62.50	306074527	10.45	37	1.16	12.08
<b>Totals</b>	171	98	57.31	983244782		179		

Southern region (89), followed by the North African (32), East African (31) and West African (23) regions. Individuals from Central Africa appear to have received the least formal ethics training (4). Once again, the Southern African region has the greatest proportion of formally trained people to the number of RECs, while Central Africa seems to have the smallest proportion.

Similar analyses can be conducted according to language regions. As reflected in Table 3 above, the greatest number of RECs known to date is from the Anglophone region (110), although only 53.64% (59) of these are listed on MARC thus far. An almost equal number of RECs are listed from the Francophone (28) and Arabic speaking (32) regions, with 67.86% (19) and 62.50% (20) of these, respectively, currently listed on MARC. The Lusophone region has the least (1) REC data available. Proportion of RECs to population is also greatest for the Anglophone region (28.40), as is the number of individuals who have received formal training (136). The number of individuals trained (136) proportionate to number of RECs (110) is also greatest for the Anglophone region (1.24), although this is only marginally larger than the same proportion (1.16) in the Arabophone region, with 32 RECs and 37 individuals trained.

It must be highlighted that the type of training referred to here is formal degree or diploma training in research

Programme. This is by no means a comprehensive picture of available training, including short courses and workshops, in research ethics occurring in Africa. However, these programmes arguably provide approximately 80% of the formal, longer-term substantive training in research ethics in Africa. See Appendix 1 of this paper for further details.

ethics, which does not account for more informal or *ad hoc* forms of training such as short courses or workshops. This problematises the very notion of 'formal' versus 'informal' training, as well as training compared to general capacity building efforts. It is estimated that the NIH/Fogarty provides approximately 80% of the formal research ethics training funding in Africa, while other training is provided by the EDCTP, TRREE, UNESCO, AMANET and WHO/UNAIDS. Certain research projects on ethical issues are also funded by the Wellcome Trust.

Some of these organisations provide training as part of an overall programme for capacity building in research ethics, in which training is just one of the capacity building and development objectives. Once again, this problematises the notion of capacity building, and where training fits into this goal. The idea behind MARC and *HRWeb* is that data collected on MARC will advance efforts in collating and pooling this information to facilitate health research ethics capacity building efforts and the development of ethical review capacity in Africa. It will also assist donors in identifying areas of need to avoid duplication of effort. The interaction of the types of data found on MARC and *HRWeb* will also assist in identifying health research priorities and aligning countries' general efforts in health systems development,<sup>52</sup> of which research ethics is a key component.

<sup>52</sup> J.H.F. Remme et al. Defining Research to Improve Health Systems. *PLoS Med* 2010; 7: e1001000.

## Country data

Table 4 below reflects country rankings according to number of RECs and according to number of people trained. Population rankings were also included for comparison. South Africa ranks highest in terms of number of RECs (35), as well as in terms of number of people trained (61). South Africa also ranks second in the proportion of people trained to population, and fourth in the proportion of RECs to population. Nigeria has the second highest number of listed RECs (19) and the third highest number of people trained (17). However, as Nigeria also has the largest population, the proportions of RECs to population and of people trained to population are relatively low. Similarly, Egypt's REC and people trained rankings are third (15) and second (27) respectively. Its large population, however, also means that it does not have a high proportion of RECs and people trained relative to the population. Tanzania ranks fourth in terms of the number of RECs (13), along with Uganda. Tanzania is also ranked fourth according to the number of people trained (10). Interestingly, although Sudan is ranked fifth according to its number of RECs, it does not come within the top five of any of the other rankings, nor is its proportion of RECs to population particularly high.

Some interesting anomalies stand out. For example, Ethiopia has the second largest population in Africa, and yet, it ranks only sixth in terms of REC numbers (6) and seventh in terms of training numbers (5). Similarly, the Democratic Republic of Congo, with the fourth largest population, ranks eighth and tenth, respectively, in terms of number of RECs (4) and number of people trained (1). There seems to be a need for further research ethics capacity building in these countries. The amount of clinical trial and health research activity occurring in these countries is a variable worthy of further investigation in future analyses of this type. In contrast, Botswana has the highest proportion of RECs to population and of number of people trained to population, despite its ranking as seventh on the number of RECs (5) listing and eighth on the number of people trained (4) ranking.

Zambia's fifth place on the number of people trained (9) ranking suggests that, as a country, it has sufficient expertise in research ethics review. However, it only ranks eighth in terms of number of RECs (4). Similarly, Zimbabwe is fourth in terms of number of people trained (10), but only seventh in terms of number of RECs (5). This suggests that, despite adequate training capacity, REC capacity in these countries is low relative to other countries with fewer trained people. Mauritius, with its small population, ranks second in the ratio of number of RECs to population. However, there appears to be no record of anyone with internationally recognised research

ethics training<sup>53</sup> in the country. A similar situation exists in Gambia and Gabon, which have smaller populations and rank fifth and third, respectively, in terms of proportion of RECs to population, but have no data to reflect whether any individuals have been trained in research ethics in these countries.

In summary, the top twelve countries in terms of the number of RECs per country are as follows: South Africa (35), Nigeria (19), Egypt (15), Tanzania (13), Uganda (13), Sudan (7), Ethiopia (6), Ghana (6), Botswana (5), Kenya (5), Cameroon (5) and Zimbabwe (5). The top nine countries in terms of number of people trained are as follows: South Africa (61), Egypt (27), Nigeria (17), Kenya (10), Tanzania (10), Zimbabwe (10), Zambia (9), Uganda (6) and Ethiopia (5). It is somewhat artificial to make an assessment of research ethics capacity proportionate to a country's population. It would be useful in future to gather data on the amount of health research activity (for example, number of clinical trials) that occurs in each country, in order to assess their proportional capacity for research ethics review.

## DISCUSSION & CONCLUSION

This paper has introduced and described the MARC/*HRWeb*-ethics platform, and presented an analysis of preliminary data on research ethics committees currently available on MARC. There are a number of benefits to using a wiki approach to connect individuals, committees and key stakeholders in research ethics. Firstly, MARC, through its host site *HRWeb*, is a platform on which Africa and the world can see what is happening in ethics in Africa and then work with that knowledge in real-time. As the platform is open, it can be used by any other REC, country or region outside Africa as well. In fact, Latin America is beginning to start mapping its own RECs on the South American equivalent of MARC on *HRWeb* and has logged over 1000 RECs to date. Second, MARC is designed to become a management information system (MIS) for RECs to manage and streamline their review procedures, proposal submission pathways and operational processes.

Thirdly, a key goal of MARC is to facilitate communication and networking between research ethics committees, particularly with a view to capacity building. Funding for this electronic networking function has

<sup>53</sup> Note again that the training referred to here is training provided by SARETI, WAB, IRENSA, MERETI and the JHU Bioethics Programme. This is by no means a comprehensive picture of available training, including short courses and workshops, in research ethics occurring in Africa. However, these programmes arguably provide approximately 80% of the formal, longer-term substantive training in research ethics in Africa. See Appendix 1 of this paper for further details.

Table 4. Country Rankings by REC and Training

REC RANKING				TRAINING RANKING				POPULATION RANKING						
REC Rank	Country	Training Rank	REC: Population Rank	Training Rank	Country	REC Rank	Population Rank	REC Rank	Population Rank	Training Rank	Country	REC Rank	Population Rank	People Trained: Population Rank
1	South Africa	1	5	2	South Africa	1	5	4	2	1	Nigeria	2	3	14
2	Nigeria	3	1	14	Egypt	3	3	29	6	2	Ethiopia	6	7	18
3	Egypt	2	3	29	Nigeria	2	1	23	14	3	Egypt	3	2	26
4	Tanzania	4	7	15	Tanzania	4	7	15	9	4	DRC	8	10	6
4	Uganda	6	10	9	Kenya	7	8	20	8	5	South Africa	1	1	19
5	Sudan	8	6	16	Zimbabwe	7	24	17	3	6	Sudan	5	8	2
6	Ethiopia	7	2	26	Zambia	8	23	17	4	7	Tanzania	4	4	15
6	Ghana	8	12	14	Uganda	4	10	9	10	8	Kenya	7	4	8
7	Kenya	4	8	20	Ethiopia	6	2	26	18	9	Algeria	10	0	9
7	Cameroon	9	16	11	Sudan	5	6	16	15	10	Uganda	4	6	10
7	Zimbabwe	4	24	8	Ghana	6	12	14	11	11	Morocco	0	0	20
7	Cameroon	8	41	1	Botswana	7	41	1	1	12	Ghana	6	8	11
8	DRC	10	4	28	Malawi	10	19	19	7	13	Mozambique	11	0	20
8	Burkina Faso	10	17	12	Cameroon	7	16	11	12	14	Madagascar	11	0	20
8	Zambia	5	23	17	DRC	8	4	28	19	15	Côte d'Ivoire	10	0	20
8	Benin	0	31	7	Burkina Faso	8	17	12	17	16	Cameroon	7	9	12
9	Senegal	0	20	13	Mali	11	21	25	16	17	Burkina Faso	8	10	17
10	Algeria	0	9	27	Libya	11	32	18	13	18	Niger	0	0	20
10	Côte d'Ivoire	0	15	21	Namibia	11	40	6	5	19	Malawi	10	8	7
10	Malawi	8	19	19	Benin	8	31	7	7	20	Senegal	9	0	20
10	Mauritius	0	45	2	Senegal	9	20	13	20	21	Mali	11	10	16
11	Mozambique	0	13	31	Algeria	10	9	27	20	22	Angola	0	0	20

  

REC RANKING				TRAINING RANKING				POPULATION RANKING						
REC Rank	Country	Training Rank	REC: Population Rank	Training Rank	Country	REC Rank	Population Rank	REC Rank	Population Rank	Training Rank	Country	REC Rank	Population Rank	People Trained: Population Rank
11	Madagascar	0	14	30	Côte d'Ivoire	10	15	21	20	23	Zambia	8	5	17
11	Mali	10	21	25	Mauritius	10	45	2	20	24	Zimbabwe	7	4	8
11	Rwanda	0	25	24	Mozambique	11	13	31	20	25	Rwanda	11	0	24
11	Tunisia	0	26	22	Madagascar	11	14	30	20	26	Tunisia	11	0	20
11	Libya	10	32	18	Rwanda	11	25	24	20	27	Chad	0	0	20
11	Liberia	0	38	10	Tunisia	11	26	22	20	28	Guinea	0	0	20
11	Namibia	10	40	6	Liberia	11	38	10	20	29	Somalia	0	0	20
11	Gambia	0	42	5	Gambia	11	42	5	20	30	Burundi	0	0	20
11	Gabon	0	44	3	Gabon	11	44	3	20	31	Benin	8	0	7
0	Morocco	0	11	32	Morocco	0	11	32	20	32	Libya	11	10	13
0	Niger	0	18	32	Niger	0	18	32	20	33	Togo	0	0	20
0	Angola	0	22	32	Angola	0	22	32	20	34	Eritrea	0	0	20
0	Chad	0	27	32	Chad	0	27	32	20	35	Sierra Leone	0	0	20
0	Guinea	0	28	32	Guinea	0	28	32	20	36	CAR	0	0	20
0	Somalia	0	29	32	Somalia	0	29	32	20	37	Congo	0	0	20
0	Burundi	0	30	32	Burundi	0	30	32	20	38	Liberia	11	0	10
0	Togo	0	33	32	Togo	0	33	32	20	39	Maritania	0	0	20
0	Eritrea	0	34	32	Eritrea	0	34	32	20	40	Namibia	11	10	6
0	Sierra Leone	0	35	32	Sierra Leone	0	35	32	20	41	Botswana	1	1	1
0	CAR	0	36	32	CAR	0	36	32	20	42	Gambia	11	0	5
0	Congo	0	37	32	Congo	0	37	32	20	43	Guinea-Bissau	0	0	20
0	Maritania	0	39	32	Maritania	0	39	32	20	44	Gabon	11	0	3
0	Guinea-Bissau	0	43	32	Guinea-Bissau	0	43	32	20	45	Mauritius	10	0	2

recently been awarded by the Fogarty International Center of the NIH. An additional objective of this funding is to develop the social networking function of MARC for members of RECs so that they can team up and engage in dialogue with each other on, for example, multi-national clinical trials.<sup>54</sup> Ultimately, MARC, through *HRWeb*-ethics, is viewed as a platform to improve the availability of information to RECs and other stakeholders so that they are encouraged to map themselves onto it, make greater use of it for networking and capacity building, and contribute to its quality by maintaining it.

### MARC and *HRWeb*-ethics: Current and future

To date, our efforts on the MARC project have centered on:

- 1) Developing and revising the process for requesting information from RECs – basic-level and second-level.
- 2) Testing and piloting the software for electronic uploading of information onto MARC via *HRWeb*.
- 3) Revising the electronic forms to be more user-friendly and tailored to the specific needs and procedures of RECs.
- 4) Contacting RECs to inform them about MARC's initiatives and inviting them to upload their information onto *HRWeb*-ethics.
- 5) Uploading basic level information on 98 RECs, and piloting second-level information on two RECs in South Africa and two in Botswana.
- 6) Establishing links with key stakeholders in the Francophone region, who will expand our REC contacts in these countries. Our project will be enriched by a contract with CAMBIN (Cameroon Bioethics Initiative) to engage with and list all RECs in Francophone African countries.
- 7) Expanding our contacts to build on our current listing of RECs in Africa.

Our immediate and longer-term priorities for future MARC work include:

- 1) Developing a MARC homepage so that MARC has an institutional identity, which facilitates referral and ease of access to *HRWeb* ethics pages, which in turn will enable better identification of RECs with the ethics function of *HRWeb*.

<sup>54</sup> NIH / FIC has awarded SARETI/COHRED a grant to develop the 'social networking' or 'community of practice' function within *HRWeb*. It is currently online in a rudimentary manner, but will be fully functional by April 2012 – enabling, for example, RECs involved in the same multi-center trials to set up their own discussion group.

- 2) Contacting those RECs already listed on MARC to invite and support them to upload their second-level information on the site and begin to use it as a resource for facilitation of protocol review and committee administration.
- 3) Expanding our database of African RECs by making contact with Francophone countries, as well as with countries from the Arabophone and Lusophone regions.
- 4) Developing a training page, which will include a database of major training programmes and funding opportunities, together with the main capacity building initiatives currently operating in Africa.
- 5) Identifying the capacity building needs of RECs in Africa – for example, training, infrastructure – through analysis of health research and ethical review data on MARC.
- 6) Expanding MARC's efforts to include developing countries on other continents, including the Latin American and Asian countries.

MARC provides a comprehensive interactive wiki-type platform to support and improve the ethics review of research for health in Africa, which, along with other critical data on REC functioning, such as member training, and on health research projects and priorities in corresponding countries, will allow for the identification of key relationships and analyses. The potential of MARC lies in the mapping of current ethical review activity onto capacity needs, which will serve an important function for researchers, funders, health research policy-makers, training and capacity-building organisations, and for RECs themselves. As MARC is funded by the EDCTP – which is limited to funding in Africa – the ethics functionality in *HRWeb* that has been developed for MARC for Africa is, of course, globally accessible, and the *HRWeb* ethics pages intend to support this global use as well.

### Biography

**Carel IJsselmuiden** (Switzerland), MD, MPH, was the founding Director of the University of Pretoria's School of Health Systems and Public Health until his appointment as COHRED Director in January 2004. Prof. IJsselmuiden, as COHRED Director, is ex-officio member of the Board, and since March 31 2011 is Executive Director of the Global Forum for Health Research, which is now merged with COHRED. **Debbie Marais** (South Africa), MA, MA, is the Research & Development Officer for the Council on Health Research for Development. She has extensive experience in research project management and coordination, particularly in the field of health research. Debbie has worked on various research and academic programmes in the School of Psychology at UKZN. She continues to work as a psychologist in the mental health field in South Africa. **Doug Wassenaar** (South Africa), PhD, is a Professor in the School of Psychology, University of KwaZulu-Natal, Pietermaritzburg, South Africa. He is a co-investigator on the MARC project, is the Director of the South African Research Ethics Training Initiative (SARETI), Chair of the UNAIDS African AIDS Vaccines

Program's Ethics, Law, and Human Rights Working Group (AAVP ELH). He is also Chair of the UKZN Biomedical Research Ethics Committee and the Research Ethics Committee of the South African Human Sciences Research Council (HSRC) and teaches and publishes in research ethics. **Boitumelo Mokgatla-Moipolai** (Botswana), MedSc, is the Senior Research Fellow responsible for managing the MARC project. She was awarded the SARETI (South African Research Ethics

Training Initiative) Masters scholarship in 2009. Prior to her SARETI training, she served in the Public Health sector in Botswana for five years. On returning from her SARETI training, Boitumelo made noteworthy contributions in the health research field to the Botswana Ministry of Health, and Princess Marina Hospital, where she served as a member of the National Health Research Ethics committee and hospital research coordinator respectively.

## APPENDIX 1

### *Trainees by Country from Formal Training Programmes: SARETI, IRENSA, JHU & MERETI*

<i>COUNTRY</i>	<i>SARETI</i>	<i>IRENSA</i>	<i>JHU</i>	<i>MERETI</i>	<i>COUNTRY TOTALS</i>
Botswana	1	2	2		4
Burkina Faso	1				1
Cameroon	1		2		3
DRC			1		1
Egypt			2	27	29
Ethiopia	1	3	1		5
Ghana	1		3		4
Jordan				5	5
Kenya	3	5	2		10
Libya				1	1
Malawi	1	2			3
Mali	1				1
Namibia		1			1
Nigeria	11		5	1	17
Pakistan				2	2
Saudi Arabia				2	2
South Africa	3	56	2		61
Sudan			1	3	4
Tanzania	5	3	2		10
Uganda		4	2		6
Zambia	2	3	4		9
Zimbabwe	6	3	1		10
<b>Totals</b>	<b>37</b>	<b>82</b>	<b>30</b>	<b>41</b>	<b>190</b>