

EDITORIAL

Beyond what we are....

Health research is an essential pre-requisite to the overall development of any country. Everyone concerned with research ethics needs to confront the greatest ethical challenge—the enormous inequities in global health. Only less than 10% of research funds are spent on the diseases that account for 90% of the global disease burden. Though 93% of the World's burden of preventable mortality occurs in developing countries, too little research funding is targeted to health problems in developing countries. Strengthening the health research capacity in developing countries is a critical need for achieving health equity.

It is essential that the developing countries create a strong national research infrastructure so that they can define priorities for health research, influence national, regional and global health agendas, and lobby for equitable allocation of resources.

Successful building of research capacity depends on national governments incorporating capacity building into their national plans, i.e. in research infrastructure. Health research capacity is the ability to define problems, set objectives and priorities, build sustainable institutions and organisations, and identify solutions to key national health problems. This definition encompasses research capacity at the levels of individuals, research groups, institutions, and nations. Investment in research capacity would need to be made for middle to long term and make a serious commitment to building local, national, and regional institutions. Autonomous research institutions attract funding and reduce administrative burdens.

According to the National Health Bulletin in Sri Lanka, lack of research culture, inadequa-

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Need higher ethical standards for Twin Research

Draft guidelines in circulation

Rapid progress of bioscience creates a strong need for continuing development of the national standards, policies and guidelines on ethics in research. We have recognised this need from the inception of the National Twin Registry of Sri Lanka (NTR). Our plan is to work towards establishing higher ethical standards when twins participate in medical research. However we intend to expand this ethical framework to cover other aspects of research involving human subjects in our part of the world.

It is possible to assign contemporary positions or streams of thoughts in bio-ethics along the lines established in the classical Hellenistic period of Western philosophy. The issues that dominate ethics in medical literature reflect the ethnocentric western philosophical and scientific tradition in which they are grounded. It is increasingly recognised that this philosophical and epistemological tradition is neither universal nor of overriding importance and that moral "rights" and "wrongs" are not absolute but may vary with the culture in which we live. Therefore our extended work will explain the philosophical basis of our arguments of the proposed guidelines from a developing world perspective.

New initiative such as ours (establishing a twin register and related genetic research) will inevitably create an essential need to bridge the existing divide between North-South bio-ethical philosophies. Our draft document on bio-ethics saw the light of the day to fulfill this need. The draft on Policy and guidelines contains 15 chapters. Some of the most important aspects discussed are ethical consideration, informed consent, data collection, documentation, storage and access to the twin data base, collection, storage and access to the human biological material including genetic material, funding, commercial exploitation, international collaboration, dissemination of results, and authorship.

We have circulated this document among national and international academics. So far we have received very encouraging comments from Prof Diyanath Samarasinghe, Professor of Psychiatry, University of Colombo, Dr. A.M.L. Belligaswatta (Director General of Health Services), Dr. Vasantha Muthuswamy, Chief of basic bio-medical research in ICMR, Secretary central ethics committee on human research, Indian Council on Medical Research, Dr. Karen J Hoffman, Acting Director, Division of Advanced Studies and Policy Analysis, Fogarty International Centre, National Institute of Health, USA, Director: Dr. Carel Ijsselmuiden, Program Southern African Research Ethics Training Initiative, School of Health Systems and Public Health, University of Pretoria, South Africa. The Sri Lanka Medical Association committee on ethics is discussing it and a feedback is expected. Many more have agreed to comment.

If you are interested, please contact us to obtain a copy. We welcome your suggestions. Let's advance our ethical approach to research.

NATIONAL TWIN REGISTRY WEB SITE

ONE OF THE FIVE HIGHLIGHTED BY THE ISTS

NTR Web site [www:http://infolanka.com/org/twin-registry/](http://infolanka.com/org/twin-registry/) is one of the 5 websites highlighted by the International Society for Twin Studies. The other 4 are 2 from Australia, one each from Netherlands and Finland. The ISTS web site can be visited through <http://www.ists.qimr.au/links.html>. We are grateful to Mr. Keerthi Abeywickrama for upgrading and maintaining the web site.

[www:http://infolanka.com/org/twin-registry](http://infolanka.com/org/twin-registry)

NEWS

MSc on Twin studies in Sri Lanka

The Board of Study Community Medicine of the Post Graduate Institute of Medicine has agreed for two of their MSc students to carry out twin studies for their theses. Dr. MRN Abeysingha, who is a member of the NTR supervisory committee and also a committee member of the Board of Study on Community Medicine, will be supervising the two students. We welcome this move and would extend our support to these two in every possible way. We wish to encourage more and more to embark the scientific inquiry in this field, which can offer a lot to our knowledge

GRANTS

The NTR has been successful in obtaining support from the Wellcome Trust, an internationally renowned research charity based in UK. These awards are competitive and, based on the scientific merit of the work.

International Collaborative Research Initiative Grants

We were awarded a grant to expand the work of the registry and to do some feasibility work. This newsletter is also supported by this grant.

Travel grants

Dr. Matthew Hotopf, Senior Lecturer, Department of Psychological Medicine, Institute of Psychiatry, Kings College, University of London, visited us to establish collaborative links and also delivered a guest lecture at the SLMA sessions.

Dr. Sisira Siribaddana, Dr. Nihal Abeysingha, Dr. DARK. Dayaratne attended workshop in Cambridge on genetics epidemiology on complex traits. These were awarded by the Wellcome Trust travel grant scheme.

Ethical clearance

We have obtained ethical clearance for the establishment of National Twin Registry project, from the Ethical Committee of the Faculty of Medicine, University of Colombo, and from the institute of Psychiatry, Kings College, University of London, to provide collaborative support.

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TWIN NEWS

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FROM:

**News Letter of the
National Twin Registry of Sri Lanka**

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