

Research Ethics from a Developing World Perspective

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(2003). *Sri Lankan Twin Registry*. Colombo, Vijitha Yapa Publications. 63 pp., ISBN 955-8095-27-3. Paperback

This slim volume marks a very significant milestone for Sri Lanka — first, for the development of the country's human research and, second, for the impetus and legitimacy it will provide for developing countries like Sri Lanka to formulate their own research ethics. The book announces to the world that the Sri Lankan Twin Registry (SLTR) aims to establish a centre of excellence for twin, family and genetic studies. The authors see twin research as uniting diverse disciplines and research methods. The aim is to develop a population-based register as well as a voluntary register if twins.

The primary tenet of the work is that ethics frameworks from developed countries may not be imposed on developing countries. The authors propose that the cultural values and beliefs of the country must be an integral part of its research ethics system, and give some tantalizingly brief references to Hindu and especially Buddhist values in Sri Lankan society. They want to bridge the existing divide between “North-South bioethical philosophies” and see this draft document (their description) as a start to achieving this end. The authors, Dr Sumathipala (a psychiatrist and clinical

researcher in Psychiatric epidemiology at the University of London) and Dr Siribaddana (endocrinologist and staff specialist in medicine at a teaching hospital in Sri Lanka) give credit to their colleagues at the SLTR and many others for their input. The book contains numerous useful references to existing guidelines for medical and genetic research, including some from the developing world. The book was developed because no single existing document was appropriate for use in Sri Lanka. Although it was prompted by the needs of the SLTR, it extends far beyond this.

The book has 12 chapters, each quite brief and including its own list of references. The chapters raise various issues for further discussion. Many, such as informed consent, data issues and the collection, storage and access to human samples, will be familiar to researchers in developed countries. Others may be less familiar, such as a proposed role for an independent third party (ombudsman) in assisting in the informed consent process. The authors suggest this through concern that the esteem in which clinicians are held in Sri Lanka might compromise patients' ability to refuse participation in research.

Language and cultural issues in obtaining consent are mentioned briefly. Concerns about commercial exploitation in the context of the internationalization of research have led to two chapters devoted specifically to these topics. The authors highlight some of the difficulties of compensating selected individuals for their participation in research when their peers are also poorly paid, and suggest that compensation may be better executed through such mechanisms as technology transfer or infrastructure development. One chapter is devoted to issues specific to the SLTR. A final appendix reviews issues concerning authorship of papers reporting research findings.

This concise book succeeds in creating an excellent basis for moving ethical research in developing countries forward. As a pioneering discussion document it will be of use not only in Sri Lanka but also to international research programs in general.

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