

Addressing ethical, social, and cultural issues in global health research

August 9 2013, by Leslie Shepherd

Resolving complex ethical, social and cultural issues in the early stage of a global health research project or clinical trial can improve the impact and quality of that research, a new report says.

The current practice for researchers is to seek approval for a study or trial from a research ethics board, usually at an academic institution, late in the process when many [important decisions](#) have already been made.

But this can leave many complex and messy ethical, social and cultural issues on the table, according to Dr. Jim Lavery, a research scientist in the Li Ka Shing Knowledge Institute of St. Michael's Hospital.

The past 20 years have seen unparalleled investment in large-scale [global health](#) science initiatives and international research consortia such as the Human Genome Project and the International AIDS Vaccine Initiative.

Dr. Lavery said these initiatives have resulted in significant scientific advance and have taught researchers a great deal about how such large-scale collaborations should be organized and managed. The Human Genome Project has also shown how the ethical implications of these initiatives could be identified and studied alongside the science.

But in a paper published today in the journal *PLOS Neglected Tropical Diseases*, Dr. Lavery and colleagues call on researchers, funders, [research institutions](#) and managers of large-scale global health initiatives to put more emphasis on understanding the ethical, social and cultural

impact of their work and to develop effective approaches to address them.

The report draws on lessons learned by the Ethical, Social and Cultural Program for the Bill & Melinda Gates Foundation's Grand Challenges in Global Health Initiative from 2005-11, for which Lavery served as co-principal investigator, along with Peter Singer at the Sandra Rotman Centre at the University Health Network in Toronto.

Some examples of the challenges addressed by Dr. Lavery and his colleagues in the ESC Program include:

- Is there a mandate for the research from the community in which it will take place? Has the community been meaningfully engaged in the research? Does the community think the research is important and has value? Have the interests of the host community been taken into account?

"Many new technologies, such as new vaccines, or new treatment strategies for tuberculosis, or new ways to control insect vectors of diseases like malaria, are tested in studies involving whole communities," he said. "But our usual approaches to the ethics of research focus almost exclusively on individuals. We had to develop some new thinking to help scientists make sure their research with communities was done to the highest ethical standards."

- How are data and biomedical specimens handled in large-scale research projects? Often researchers will collect data or [tissue samples](#) in one country, take them back to European or North American labs for study, and then send the results back to the host community, without involving the community in the process.

Working with a large international research project to improve the understanding of the impact of malaria, Dr. Claudia Emerson of the ESC Program at the Sandra Rotman Centre developed a "tissue trust" model that recognized the cultural significance of the blood and tissue samples and improved the collaborations with the host country scientists and communities.

"In North America and Europe we tend to focus on privacy issues when blood and tissue samples are involved, but in low- and middle-income countries these samples can have deep cultural significance to communities and therefore ownership and appropriate stewardship of these samples are the main concerns," Dr. Lavery said. "The 'tissue trust' solution is a great example of how our ESC Program works. It was only possible because of a close working relationship with the scientists over several years. It privileged the perspective of the host communities and our collaborators in the South. And it resulted in a practical solution that directly addressed the real ethical problem, and that can be applied and refined for a wide variety of other research projects around the world."

More information: [www.plos.org/wp-content/uploads/...
d.0002227.Lavery.pdf](http://www.plos.org/wp-content/uploads/2013/08/0002227.Lavery.pdf)

Provided by St. Michael's Hospital

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