Ethics reflection in development cooperation: a critical role for The Union

A SUBSTANTIAL and much valued component of the work of the International Union Against Tuberculosis and Lung Disease (The Union) has always been its role as a pathfinder in devising effective lung health services, based on rigorous research, particularly in low-income countries. In industrialised countries it is routine practice for research proposals to be subject to independent ethical scrutiny before they are implemented. The ethical dimensions of co-operative activities in low-income countries have not been addressed to any great extent, but clearly need to be. Reviews of both research and service proposals are especially important where there is an imbalance of power and resources between cooperating partners. There has hitherto been no formal mechanism for independent ethical review of projects in which the Union is involved, save where this was carried out under the auspices of one or more of its collaborators. With these considerations in mind, in 2004 the Union established an Ethics Advisory Group, with a brief to evaluate and highlight ethical issues in its research proposals, projects for development of lung health services and other international cooperative activities.

The Group comprises five persons drawn from around the world with relevant professional and personal credentials and practical experience in development cooperation, guided and assisted by a Senior Advisor of the Union. They include representatives of public health, clinical practice, patients’ experiences, social sciences and faith-based community leadership. Four of the five come from countries with a high burden of tuberculosis. The Group is mandated always to place first the interests of patients and their communities, without prejudice or the influence of external agencies.

The Group meets annually. Between formal meetings, business is conducted by e-mail correspondence. To date it has reviewed nine research proposals in which Union staff are principal investigators or collaborators. Comments and suggestions on each have been submitted to applicants for their consideration, with requests for revisions if necessary. A set of Policy and Operational Guidelines has been compiled. These include an analysis of the ethical responsibilities of the Union in all its international activities, procedures for applying for ethical approval of research protocols, definitions of research, information that should be supplied to participants, requirements relating to informed consent and the criteria by which applications will be assessed. These are available in electronic format from the Union website (www.iuatld.com) or in hard copy from the Union Secretariat.

The Group further aspires to foster within the Union, and more generally, reflection and discussion of ethical issues arising from its diverse work in education, technical assistance, research and advocacy. A start has already been made through the Union’s own educational and scientific programmes. The 2006 World Conference in Paris included a workshop sponsored by the Ethics Advisory Group on Ethics Issues in Union Research and Development Activities. In addition, an eminent nominated speaker addressed a plenary session on the topic of ethical issues in clinical trials in high burden countries. An article by Dr Benatar appears in this issue of the Journal.1 A symposium on the importance of ethical reflection in Union activities is planned as part of the 2007 World Conference in Cape Town. There are also plans to sponsor short courses on the elements of ethical research projects.

The Group’s vision is that a climate of ethical reflection should pervade all activities of the Union and its relations with others. This is a universal value and one to which the Union already wholeheartedly subscribes. To this end, the Group solicits the engagement of the entire constituency of the organisation in promoting and supporting all initiatives that aim to address ethical issues.

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