



## **BIENNIAL REPORT OF THE IARC ETHICS COMMITTEE (IEC), 2011–2012**

1. The IARC Ethics Committee (IEC) ensures the protection of the rights and welfare of participants in studies carried out or sponsored by IARC, through the consistent application of the highest ethical standards for research involving humans. The Committee is composed of twelve senior individuals. It meets every two months to give an ethical evaluation of all IARC projects within its competence. Meetings take place in Lyon with participation by videoconference for international members of the Committee.

### **Composition of the Committee**

2. The IEC comprises seven external members from diverse backgrounds, four IARC staff members and one WHO staff member:

#### *External members*

- Professor Clement Adebamowo (Nigeria), surgeon and bioethicist
- Professor Jean-Pierre Boissel (France) (Chair), emeritus professor of pharmacology
- Dr Béatrice Fervers (France), oncologist
- Dr Marc Guerrier (France), ethicist
- Mr Yazid Ikdoumi (France), lay member
- Dr Pierre-Jean Souquet (France), pneumologist
- Professor Paolo Vineis (UK) (Vice-Chair), epidemiologist

#### *IARC and WHO staff*

- Ms Evelyn Bayle (Screening Group, IARC)
- Dr Martyn Plummer (Infections and Cancer Epidemiology Group, IARC)
- Dr Abha Saxena, Geneva (Secretariat of the Research Ethics Review Committee, WHO)
- Dr Ghislaine Scélo (Genetic Epidemiology Group, IARC)
- Dr Eduardo Seleiro (Director's Office, IARC)

#### *Secretary to the IEC*

- Ms Susan Haver-Legros (Director's Office, IARC)

3. Since April 2010, Professor Jean-Pierre Boissel has been IEC Chair and Professor Paolo Vineis, IEC Vice-Chair. All other members of the IEC were appointed in January 2010 except for Dr Eduardo Seleiro who was appointed in February 2011. Dr Ghislaine Scélo became a member of the IEC in September 2012 as she replaced Dr Bakary Sylla upon his retirement from IARC. The presence of a member of the secretariat of the WHO Research Ethics Review Committee (Dr Saxena) ensures consistency with WHO ethical review practice.

### **Activities of the Committee**

4. During the period 2011–2012, the IEC met 10 times (February, April, June, September and November of both years) and 73 projects were evaluated:

- 53 were cleared after first ethical review;
- 7 were given conditional approval, i.e. Principal Investigators were requested to make specific changes or provide additional information before their projects were given ethical clearance (five were subsequently cleared; two are pending); and
- 13 projects were rejected and the Principal Investigators were asked to prepare a revision for re-submission (five were subsequently cleared; six are pending and two were not resubmitted).

5. During this period the Standard Operating Procedures (SOPs) were also updated to better define the requirements and process for periodic reporting to the IEC. All studies involving active contact with participants must report annually to inform the IEC of any ethical issues arising in the conduct of the study.

6. Two Special IEC Sessions have been held over the past two years. The first was on the societal impact of the IEC's work, following IEC concerns on the dissemination of research findings and was held at IARC on 7 December 2011, in the presence of the IARC Director, Dr Wild. The second on the topic of incidental findings, particularly within the context of human genomic studies using the new exome or whole genome sequencing methodologies, was held at IARC on 27 June 2012.

### **IARC Ethics Advisory Group (EAV)**

7. The IARC Ethics Advisory Group (EAV) is a small group of international experts. It has been constituted to provide specialist expertise to the IEC to help resolve complex ethical issues. The members are as follows:

- Professor Sheila McLean, Emeritus Professor of Law and Ethics in Medicine, University of Glasgow;
- Professor Michael Parker, Professor of Bioethics and Director, The Ethox Centre, University of Oxford;
- Dr Rodolfo Saracci, Senior Visiting Scientist at IARC and former Chair of the IARC Ethics Review Committee (1982–2005).

8. The EAV was consulted for the first time in December 2011 concerning the topic of incidental findings. This particular issue has given rise to considerable debate by the IEC during 2012 in an effort to formulate a policy in an area in which ethical standards are still not well defined.