

Ethics networks at the European and national level

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Ladies and Gentlemen,

Allow me, please, to start my contribution with an “anecdote”, reported by a visitor of a horse race to his friend:

»As I was standing at the fence, the wind blew off my hat and took it directly to the track. I jumped over the fence to rescue it and at that very moment the race started.«

»Oh, dear,« said the excited friend. »What did you do then?«

»I did my best, I finished second«, was the short reply.

When I was invited to talk about networking in ethics, I felt like my hat had just been blown away. However, as I could not refuse the kind invitation, I started to search for the data which I could present at this meeting – according to the proposed title of my presentation – a review of the ongoing European international and national networking in ethics, going on in a form of cooperation of various ethics bodies, institutions, and in a form of the EC Framework projects. As I could not find a review published so far to start with, I searched the Internet. Even after excluding the non-European websites, a large number of web pages remained to be studied.

Being rather reluctant to jump after my blown-off hat, my heart sank when I got a glimpse of the elegant, sporty, muscular and vigorous horses from the UK, Germany, France, Scandinavian countries, to name just a few. I decided to leave my hat to its destiny and rather try to give you a short report on the participation of my own horse, the NMEC, in this lively race called European networking in ethics. So the proposed title was adjusted accordingly, and now reads –

Ethics networks at the European and national level – the Slovenian perspective

It is logical and well-known that cooperation of people, bodies and institutions active in ethics did not start with the appearance of the term “networking”, now referring predominantly to the ICT (information and communication technology) mode of interaction. However, there is no doubt that the ICT, especially with the Internet, makes work considerably easier and better.

In the NMEC, we started to search the Internet in the late nineties for information that was not available in the acknowledged bibliographic databases, for example about ethical and legal aspects of research on human beings and various new therapeutic interventions. Unfortunately, most often the best information that could be reached was a telephone number or a name and address of an institution or person, so that further “networking” was done the traditional way – by personal communication, by telephone, e-mails, letters, and discussions at various meetings. We took part in a few international bodies and organisations, e.g. in the CDBI (Steering Committee on Bioethics) and

Cometh of the Council of Europe. We followed the activities of the UNESCO, WHO, European Group on Ethics of the European Commission, the European Forum for Good Clinical Practice etc. The networking of these organisations, at that time, was also mainly done in the traditional way, communication and exchange of information being the most effective at the meetings.

We were delighted by the invitation in 2001 to participate in the 5th Framework database-related networking project known under the acronym of EURETHNET. Its main two subprojects were EUROETHICS and ENDEBIT. The former was aimed at substantially expanding the existing European database on ethics in medicine and health care (Euroethics Health Network, EHN), and the latter was to establish a database network on ethics in biotechnology. We participated in EUROETHICS, to which our collaborators from the Institute of Biomedical Informatics (IBMI) contributed the basis – a system for the on-line up-grading and searching the database. The project was officially closed in 2005, however, the partners committed themselves to continue updating the database. I am still receiving weekly backups of new contributions of the former EU candidate states on CDs, but I am afraid the contents have long been the same. The enthusiasm, needed for our work in the ethics committees, is obviously consumed by other pressing duties of everyday.

We also participated in another FW5 project called PRIVIREAL, which examined the implementation of the Data Protection Directive (95/46/EC) in relation to medical research and the role of ethics committees in Europe.

After becoming a member of the EU, Slovenian NMEC in its power of a NEC, joined the NEC Forum and, actually, organised, in cooperation with the EC, its most recent meeting last February. Networking in this group is quite active, with new initiatives for work in subgroups.

We are well aware of another network, EUREC, which joins national networks and associations of Research Ethics Committees (RECs) in Europe. Considering our limited capacities for contribution, we have hesitated to join. When our reform of the NMEC, namely the division of its workload between a REC and a NEC, is accomplished, the new REC will hopefully compensate for this deficiency. We suspect that the situation may be similar in the majority of the EU states, as, reportedly, only 9 have joined the network so far.

This year, a FW7 project, ETHICSWEB, is to be launched with participation of the IBMI (and NMEC) in a group of 18 partners. It is aimed at building-up a European Documentation System in ethics which will virtually connect existing infrastructures, databases and networks, including international organizations, which deal with ethical and legal questions, like WHO, FAO, and UNESCO.

The project PRIVIREAL will continue under a new name of PRIVILEGED, also with our participation.

In Slovenia (with 2 million population), the NMEC has the power and obligations of the central REC as well the NEC. Its connections with local Institutional Review Boards (IRB) are irregular. I don't have the capacity or the time to talk about national networking in ethics in the larger EU states.

Before the conclusion, I may remind you of yet another website which became operational recently, the Sinapse (Scientific INformAtion for Policy Support in Europe), operated by the EC. It is not primarily an ethics website, but as it provides a forum for communication across Europe, it also covers ethical issues. The NMEC has joined it, because we expect that this may soon become a horse to bet on. It is obviously taken care of by dedicated professionals and its financing seems secured in the long run. As proven by several projects in ethics and by daily overload of many a voluntary REC or even NEC, ethics matters, unfortunately, can no more be driven solely by the ethics fuel. Financing is crucial also for the networking in ethics. Admitting that, I would, however, like to point out that the cost benefit assessment should be even more strictly observed here than in other projects, not only from the economic point of view, but – primarily – with regard to the distributional and “green” ethics. E-inclusion of networking in ethics can definitely fulfil these stricter criteria. Physical presence at meetings should be replaced by the ICT, whenever possible.