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RESEARCH DIRECTORATE-GENERAL

Directorate C - Science and society
Scientific advice and governance

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EU Forum Science in Society
Report of the specific session
“Civil Society and Science: an increased role for NGOs?”
Thursday 10 March 2005

Participants in the Round Table:

Chairperson: *Willem Halfman*, University of Twente, NL

- *Eszter Markus*, EMLA (Environmental management and Law Association), Budapest
- *Claudia Neubauer*, FSC, Fondation Sciences citoyennes, Paris
- *Anne-Sophie Parent*, AGE - the European Older People Platform, Brussels
- *Douglas Parr*, Greenpeace, London
- *Frank Rodenbourg*, EATG, European Aids Treatment Group, Paris
- *Tamsin Rose*, EPHA, European Public Health Alliance, Brussels

1. SETTING THE SCENE

The aim of this initiative was to discuss ways and means of stimulating the involvement of NGOs and other civil society organisations in the European Research Area. The chairperson asked participants to express their views on the following issues:

➤ **Stakes and experiences:**

What is your ‘stake’ as a ‘stakeholder’ in research and, as such, what do you want to achieve? What are your past experiences at national level, and with the EU and its research policy? Can you identify what works well and what doesn’t?

➤ **Recommendations:**

What are your recommendations to increase the involvement of NGOs in EU research policy? (in particular in view of the 7th Framework Programme)

2. A SHIFT IN THE ROLE OF NGOs IN RESEARCH

2.1. *The past experience*

As described by the participants, NGOs usually act as watchdogs and advocacy organisations to promote a different vision of the world and/or to defend the interests and needs of their members.

NGOs' involvement in the European Research Area is very limited. When involved (a few cases mentioned by AGE, FSC and EPHA), it is more often as "objects" of research or at a later stage, mainly in the dissemination phase. The participants regretted the limited attention given to policy concerns and to non-for-profit actors. They¹ criticized the lack of remuneration of the time and resources they are asked to invest in research projects by coordinators.

EATG related years of chaotic dialogue between associations defending patients' needs and pharmaceutical industries and research centres. In France, eight associations grouped within TRT5 are acting as main interlocutors to pharmaceutical labs and the national aids research agency. TRT5 achieved some success in influencing clinical trials.

The participants reported growing concern, loss of trust and even suspicion in relation to research priorities setting, research processes and the impact of research findings. EMLA mentioned the partial information given on the impact of Chernobyl in Hungary. AGE argued that patients are captive consumers since they have little or no choice in the treatment prescribed to them and called for independent and reliable information to be available to them.

2.2. Towards a sustained participation throughout the research policy cycle

While maintaining a critical position and without being turned into research organisations, they are willing to strengthen their involvement in research and develop a partnership on a more regular basis with research actors throughout the whole cycle of research policy.

Their objective is to instil human/ social concern and values in research activities at different stages of the research policy cycle, in setting research agendas, implementing research, assessing and discussing research results in the light of their members' interests and needs.

They also asked for fuller recognition of their experience and knowledge by researchers and acknowledgment of the need for public testing of expertise. They requested appropriate funding from public funds to enable them achieve their role in complete independence from other interested parties such as industry.

Civil society organisations are already actors in research and expertise (referred as "tiers secteur scientifique" in France). CSO² research is conducted in domains such as health, environment, agriculture, energy, discrimination. The resulting knowledge serves citizens' needs (on a local, national or global level) and is constructed in a collective way, including various types of knowledge appropriate to solve problems often of high complexity.

3. SUGGESTED ROUTES THROUGH THE EUROPEAN RESEARCH AREA (ERA):

3.1. NGOs involvement in setting research agendas

The participants pleaded for public engagement at an early stage of the research policy process. They stressed the need for adequate information to enhance their

¹ Apart from Greenpeace which doesn't accept "Government or corporate" funding for its activities

² Civil Society Organisation

understanding of the issues at stake and their ability to contribute to the definition of research objectives.

1. *Preparing the ERA Framework Programme and its Specific Programmes*

This involves voicing their concerns and opinions to the European Institutions (Parliament, Council and Commission) in due course during the process. FSC and Greenpeace presented a petition elaborated by the European Science Social Forum Network³, which proposes an alternative research agenda for FP7. According to EPHA the whole ERA should be renamed “Science and Society”.

2. *Discussing research priorities in the different domains covered by ERA*

This implies participation in networks and other structures involved in the preparation of research work programmes (such as advisory committees).

Era-net schemes have been mentioned, which support networking and coordination of national research programmes and may involve different stakeholders (researchers, policy-makers, NGOs, etc). For example ERA-AGE, which involves AGE, brings together 14 national research programmes on ageing to share good practice, avoid duplication, build synergies on common goals and develop methods for joint research activities. EATG asked why a previous suggestion to set up an EU network on clinical research on aids was disregarded.

3. *At national, regional or local level*

FSC noted that science shops are constructive examples of interaction between NGOs, universities and researchers at local level. Science shops provide independent, participatory research support in response to concerns experienced by civil society. They are important actors in community-based research. Transnational networking between the science shops should be encouraged. Reference was also made to community research councils in the UK.

4. *At project level*

It was suggested to provide specific funding to NGOs for research priority setting or for preparing research projects. Reference was made to Community-University Research Alliances in Canada⁴. They support the creation of NGO-university alliances to promote the sharing of knowledge, resources and expertise with a view to enrich research, teaching methods and curricula in universities, to reinforce problem-solving capacity of associations; and to enhance students' education and employability. A similar programme, “Partenariats Institutions et Citoyens pour la recherche et l'innovation” (PICRI) has been recently introduced in France.

3.2. *NGOs' role in implementing research projects*

To engage NGOs in research projects calls for adaptations on both sides:

- current financial instruments should be more suitable to NGOs' participation or specific ones should be provided (in analogy with what has been done for

³ available on their website: www.essfnetwork.org

⁴ http://www.sshrc.ca/web/apply/program_descriptions/cura_f.asp; Two-step procedure to allocate funds: lump sums to prepare projects followed by specific funding of selected research projects.

SMEs in FP6); and researchers should be more open to their knowledge, suggestions and needs;

- NGOs should develop their ability to shape research questions, to conduct research in support of their concerns and needs, to dialogue with researchers and to assess the impact of research findings.

1. In the guidelines and management of calls for projects:

The following suggestions were made:

- Request applicants to explain how (when relevant) they consider the concerns and participation of civil society organisations in the project;
- Establish guidelines to involve NGOs and their members in relevant research projects, for example on health, social sciences, new technologies, etc.
- When selecting projects, assess how civil society concerns and participation is integrated (qualitative assessment);
- Involve qualified NGOs members in evaluation teams. For example, FSC and EMLA members were evaluators of projects submitted under a recent call of the Science and Society section of the FP 6 specific programme “Structuring the ERA”-2002-2006.

2. As partners in projects

The round table participants underlined that adequate funding in resources (time, staff, etc) is crucial to enable NGOs to participate in research projects. It was suggested that funding could be allocated on defined work packages for each partner within projects.

3. As project coordinators

Participants suggested that NGOs could also coordinate projects with a view to:

- examining science and society issues and controversies to identify research questions and look for innovative approaches;
- developing methodologies and tools to involve NGOs in research (participatory processes);
- preparing or supporting specific research projects;
- assigning to RTD performers research based on questions they would have defined with relevant partners (public authorities, industries...)⁵
- analysing the context (social, cultural, health, economic and environmental), the limits and impacts of research findings and new technologies, and elaborating impact assessment tools and processes

3.3. Dissemination and appropriation of research findings by NGOs

The participants called for more resources to be allocated to dissemination of research findings and their appropriation by the stakeholders concerned. They would like not only adequate information on research findings but also more opportunities to discuss the findings with researchers and other stakeholders. For example, EATG

⁵ In analogy with CRAFT, specific financial tool developed for SMEs

claimed that patients participating in clinical trials and their associations should be informed and involved not only during the trials, but also earlier in the preparation phase, and afterwards to assess the results. Participants also asked that results of EU funded projects are put in the public domain and are accessible to all.

4. FUNDING NGOs RESOURCES SPENT ON RESEARCH ISSUES.

The participants reported difficulties in the access to RTD calls that they relate not only to financial constraints (i.e. required co-financing at 50 %) and administrative complexity, but also to the lack of interest/recognition of research performers to work with NGOs.

They underlined the importance of adequately funding activities that they would perform or in which they would participate, such as participation in enquiries/ consultations, feasibility studies, involvement in the project steering/ monitoring groups, networking, training, participation in meetings, dissemination of research results (websites, publications, etc), organisation of panels/ debate to discuss and evaluate research results, etc.... It was also suggested making funding available for the secondment of researchers from research centres to work directly with NGOs teams for a given period.

5. OPENING THE DEBATE TO THE AUDIENCE

The debate which followed highlighted similar concerns (taken into account in the above chapters). In addition, a representative of the Church of Scotland regretted that churches were not invited to participate in the round table. Some questions related to the means to assess the “legitimacy” of NGOs. The participants suggested looking at organisational and income structures, membership and outputs. AGE explained that, in addition to the registration in the Commission directory CONECCS⁶, the NGOs grouped under the European social Platform asked the Commission for a consultative status on grounds similar to the Council of Europe’s system. The NGOs stressed their call to make information about their sources of funding publicly available with a view to increasing their legitimacy.

⁶ http://europa.eu.int/comm/civil_society/coneccs/index_fr.htm