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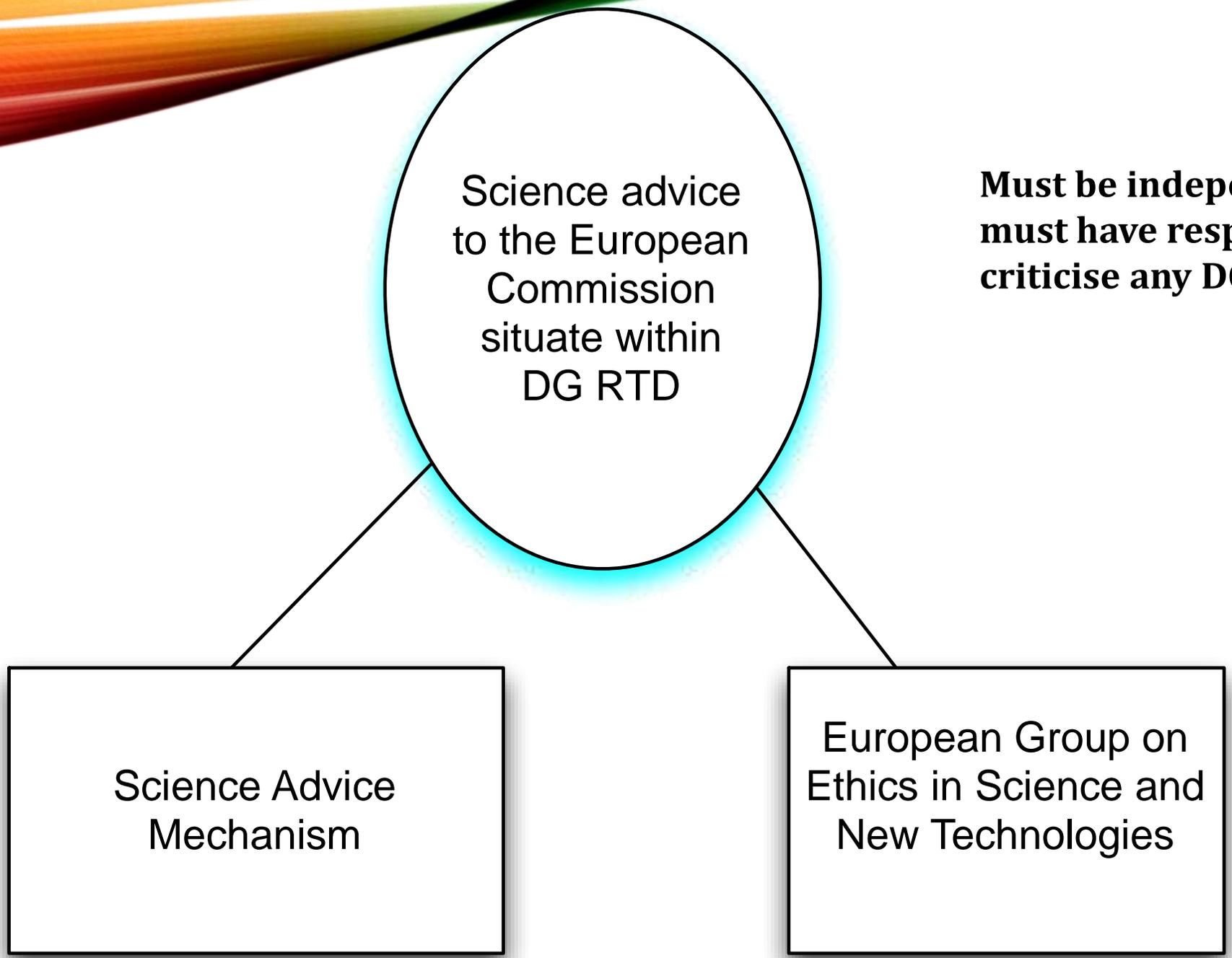
**How science projects can be used to
influence policy advice and implementation
in the EU and SA**

Julian Kinderlerer



WHO AM I?

- **Emeritus Professor of Intellectual Property Law, UCT**
- **Former Professor of Biotechnology and Society, TU Delft**
- **Former Director, Sheffield Institute of Biotechnological Law and Ethics and Professor of Biotechnology Law, Sheffield**
- **President, European Group on Ethics in Science and New Technologies, European Commission**



Science advice to the European Commission situate within DG RTD

Must be independent, and must have responsibility to criticise any DG

Science Advice Mechanism

European Group on Ethics in Science and New Technologies

SCIENCE ADVICE MECHANISM

As announced by President Juncker on 13 May 2015, the European Commission has set up the EC **Scientific Advice Mechanism ("SAM")**. **Its aim is to support the Commission with high quality, timely and independent scientific advice for its policy-making activities. This will contribute to the quality of EU legislation, in line with the Better Regulation agenda.**

- Janusz M. Bujnicki (Warsaw)
- Pearl Dykstra (Rotterdam)
- Elvira Fortunato (Lisbon)
- Rolf-Dieter Heuer (CERN)
- Julia Slingo (Exeter)
- Cédric Villani (Paris)
- Henrik C. Wegener (Denmark)



The EGE has been an independent, pluralist and multidisciplinary body advising the European Commission on ethics in science and new technologies in connection with Community legislation or policies. The EGE members serve in a personal capacity and are asked to offer independent advice to the Commission, Council and Parliament

It consists of 15 members, approximately 5 scientists, 5 lawyers and 5 ethicists/philosophers/theologians

It provided advice on issues referred to it by the Commission or on topics which it chooses itself



“The Union is founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities. These values are common to the Member States in a society in which pluralism, non-discrimination, tolerance, justice, solidarity and equality between women and men prevail.”

We hold these values as fundamental to the effective working of the European Union and of society in general, and believe that these distinguish the EU from so much of governance today.



EGE

- We are asked to draft Opinions on particular issues that the Commission believes need a detailed examination and exposition of the ethical issues underlying the topic.
- We take evidence from government and Commission Officials, scientists and others interested in the topic. In particular, we ask those involved in projects funded by the EU to inform us
- We hold an open (televised) round-table at which we gain advice from any source
- We may also draft statements and Opinions on our own initiative



Opinion on the ethical implications of new health technologies and citizen participation

Recent years have witnessed a wave of innovation in health technologies driven by new medical breakthroughs, novel scientific approaches and the rise of digital health technologies. Pioneering methods of drug development and disease diagnosis, the rise of 'big health data', and new means of providing networked care have led to predictions that European health systems are on the cusp of transformation. While much of the promise held in these technological innovations remains to be fully realised, the rise of new health technologies are accompanied by a profound set of shifts in the way individuals – whether as patients, citizens or consumers – engage with matters of health.



HEALTH TECHNOLOGIES

The 'participatory turn' in health offers a number of new roles to citizens, whether as experimenters, stakeholders, purveyors of data, research participants, or users. It covers not only the gathering and volunteering of data, and the involvement of non-experts in scientific experimentation and analysis, but also the lobbying efforts of interest groups, public input into research and funding, as well as in the formulation and regulation of policies. Citizen involvement manifests at different stages in the process – from upstream interventions in priority setting, and influencing funding decisions to a more direct downstream involvement of citizens and patients in the use and application of medical knowledge and information. It covers both those active, informed participants who engage from a position of agency as well as those unaware of their contribution.



The President of the Commission asked for a statement on the ethics of information and communication technologies

We interviewed many of those involved in EU funded projects on anything which related to this topic

Opinion No. 26

Ethics of Information and Communication Technologies

Brussels, 22 February 2012

On 21 March 2011 President José Manuel Barroso asked the EGE to draft an Opinion on the ethical issues arising from the rapid expansion of information and communication technologies (ICT). President Barroso indicated that the Opinion could 'offer a reference point to the Commission to promote a responsible use of the Digital Agenda for Europe and facilitate the societal acceptance of such an important policy item.

The EGE is aware of the changes that have come about in the lives of most citizens of the European Union, and further afield, as a result of the pervasiveness of new electronic media. The challenge is to ensure that the availability of electronic information and the use of ICT are handled in an ethical manner.



Opinion No 27

An ethical framework for assessing research, production and use of energy

Brussels, 16 January 2013

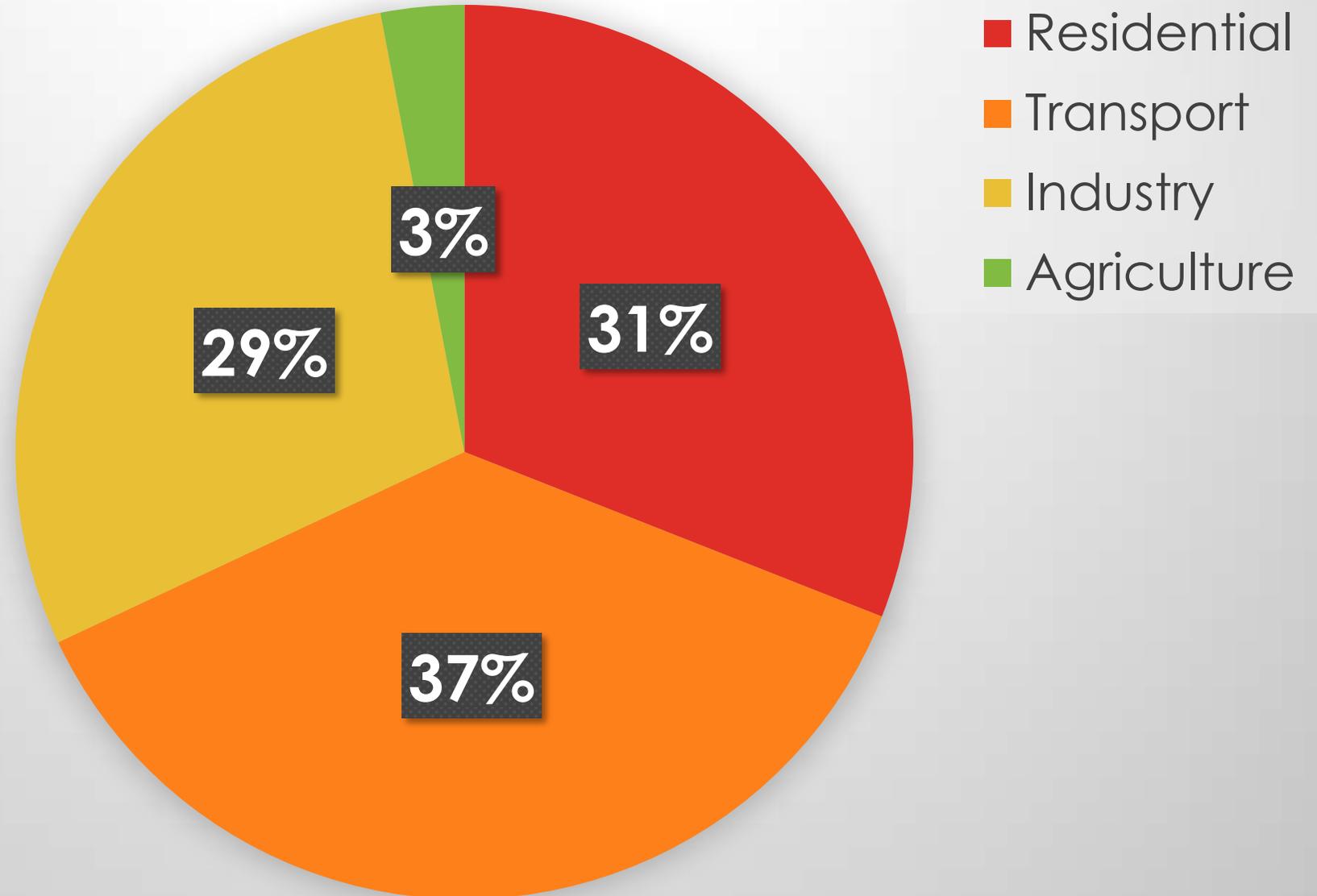
We were asked by the European Commission President and the Council to provide them with an Opinion on (primarily) ethical issues related to research on Energy production. We drafted an Opinion on an ethical framework for assessing research, production and use of energy

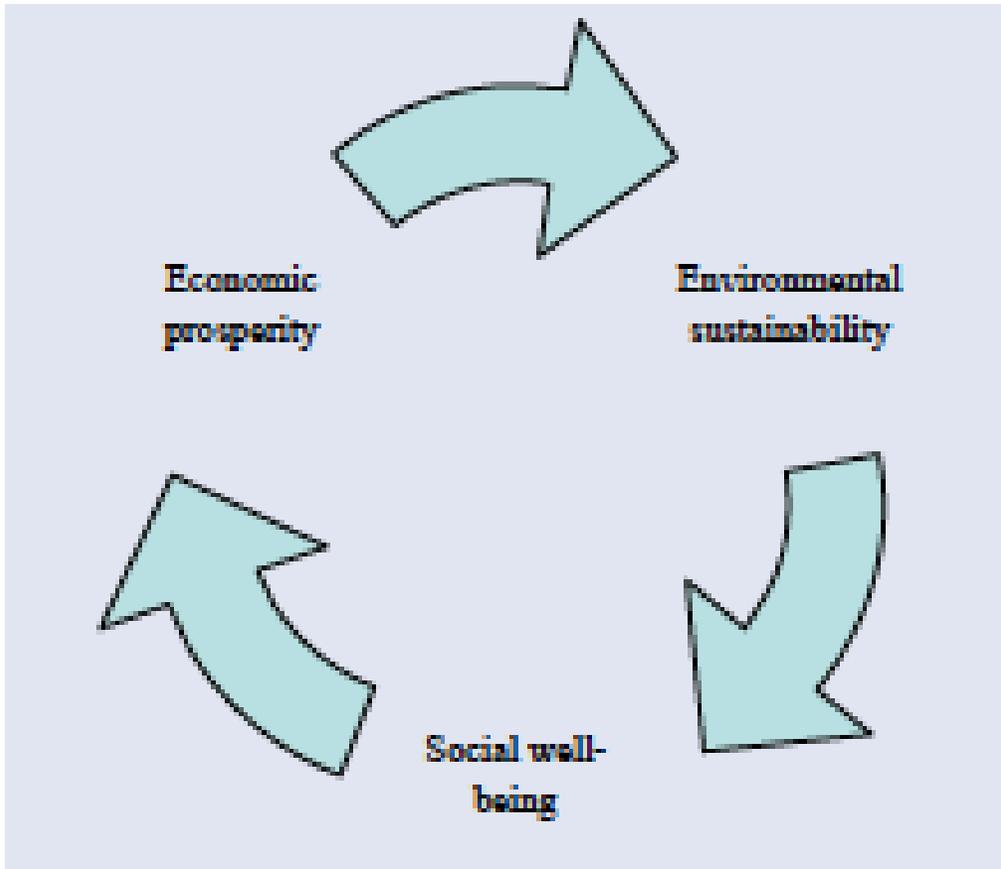


ENERGY

On 28 June 2011 the Council reached a political agreement on a Commission proposal for a nuclear research and training programme for 2012–13. Although the Council's discussion has been successfully concluded, some Member States felt that a broad discourse on ethical issues and sustainable energy mix in Europe should take place and indicated the need of having an independent Opinion of the European Group on Ethics in Science and New Technologies (EGE) on this topic. On 19 December 2011, the President of the European Commission requested the EGE to 'contribute to the debate on a sustainable energy mix in Europe by studying the ethical impact of research on different energy sources on human well-being.'

Energy use



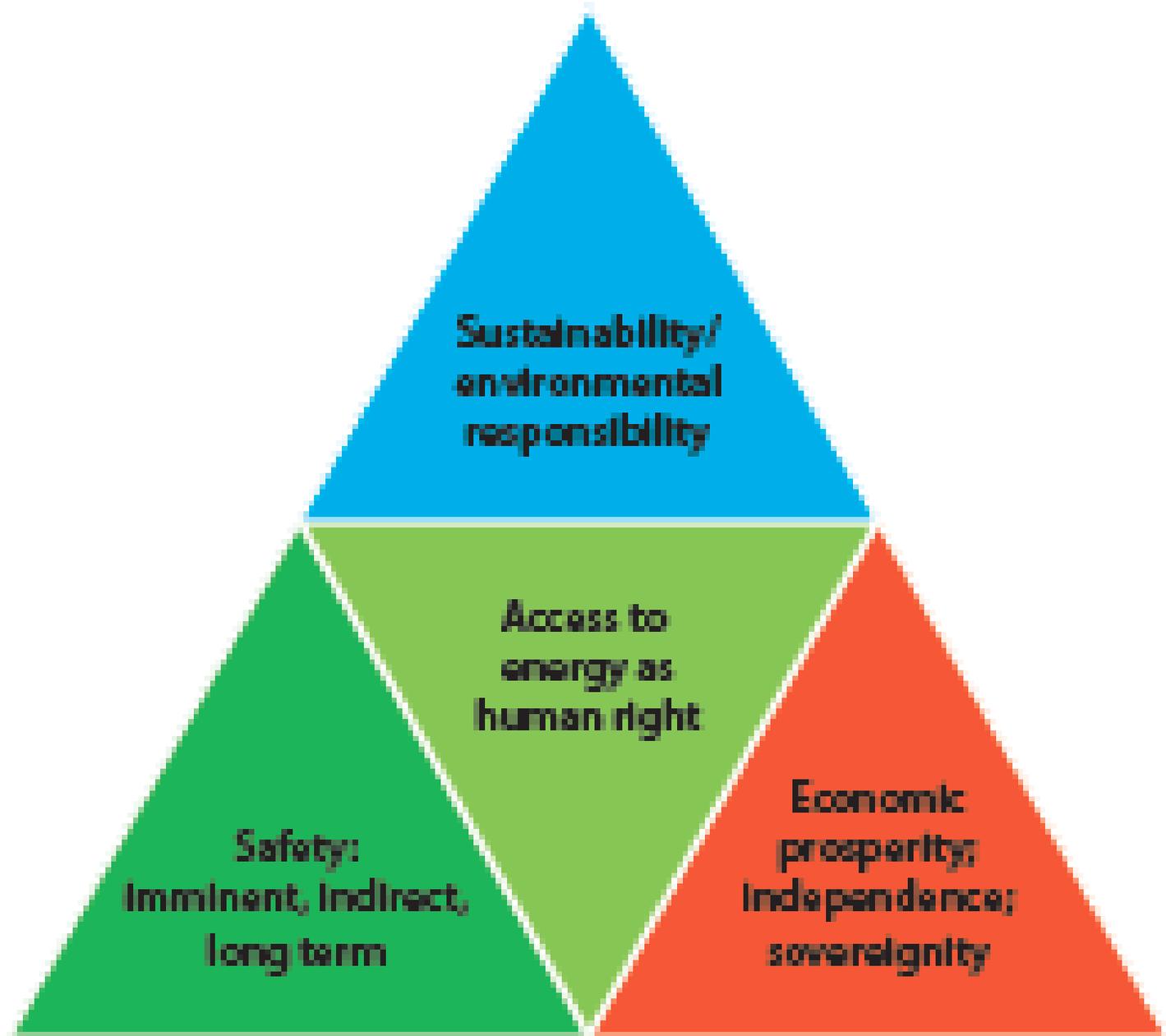


Europe's energy policy becomes one of the greatest tests that Europe has to face in the coming decades. It is important to address the EU energy policy in the light of the Lisbon Treaty's Energy Policy objectives:

- (a) ensuring the functioning of the energy market;
- (b) ensuring energy security;
- (c) promoting energy efficiency and energy saving, and the development of new and renewable forms of energy; and
- (d) promoting the interconnection of energy networks.

HENCE:

- security of supply;
- affordable access to all users;
- increasing dependence on imports,
- climate change and the necessity to enable the transition to renewable energy;
- strain on energy resources;
- the issue of diversity of energy mix;
- the need of a coherent external energy policy;
- the equilibrium between the principle of subsidiarity and autonomy of Member States;
- solidarity among Member States; and





OPINION NO. 28 OF THE EUROPEAN GROUP ON
ETHICS IN SCIENCE AND NEW TECHNOLOGIES

Ethics of Security and Surveillance Technologies

Brussels, 20 May 2014

On 21 March 2011 President José Manuel Barroso requested the EGE to draft an Opinion on the ethical implications of information and communication technologies and to produce, subsequently and separately, an Opinion on the ethical implications of security technologies, with due attention given to the development of security technologies and to surveillance technologies. The present Opinion addresses the issues of security and surveillance technologies from an ethical perspective. As the group prepared the report, the revelations of Edward Snowden emphasised how important a reorganisation and reinterpretation of our approach to security and surveillance is. Indeed the predicament of data flows and surveillance activities thrown into sharp relief by these revelations form part of the evolving backdrop against which this Opinion is set.



SECURITY AND SURVEILLANCE

National security is the responsibility of the Member States, but the Lisbon Treaty, and particularly the Charter of Fundamental Rights embedded in it provides for action by the Union where necessary to protect the rights of individual citizens. In addition, the EU shares competence with member states as regards the internal security of the Union and has established an Internal Security Strategy to identify and coordinate action against common threats.

In this opinion we address the manner in which surveillance has been enhanced due to the availability of new technologies and the means to record and analyse and retain vast amounts of data provided by advances in information and communication technologies.

SECURITY AND SURVEILLANCE

Accountability

Member States need to ensure that those granted powers to surveil the private sphere of citizens are acting in the public interest and are accountable for their actions. Where the State delegates security and/or surveillance tasks to private companies, they are bound by the same legal and ethical obligations and Member States should put in place mechanisms to monitor compliance with these obligations

Towards a common understanding of national security

The shared European values enshrined in the EU Charter of Fundamental Rights represent the normative framework on which a common ethical understanding of national security could be built.

a) While recognising that national security is legitimately placed at the heart of national interests and is a competence of Member States, the EGE recommends that EU institutions in conjunction with Member States should find ways to establish such a common understanding of national security.

b) The EGE also recommends that Member States should establish procedural means to keep other Member States appropriately informed of extra jurisdictional intelligence activities in order to preserve trust between partners.

c) Member States should not in the name of national security surveil other Member States for commercial advantage, because it conflicts with the EU objective of achieving a single European market.



European Group
on Ethics in Science
and New Technologies
to the European Commission

Ethics of modern developments in agricultural technologies

We have drafted a number of other Opinions including issues like Agricultural technologies, guideline for the use of embryonic stem cells in EU funded research.

SCOPE

- Food security, energy security, sustainability and globalisation have become core issues in the current political debate worldwide. This debate is enriched by other issues, including climate change, global trade, fluctuations in food and energy prices and the future need for additional energy sources, the revision of the EU common agricultural policy (CAP) and the link between the CAP and the EU economic strategy (the 'Lisbon agenda').
- In order to address the new challenges and opportunities which lie ahead for EU agriculture, President Barroso asked the EGE to prepare an opinion on the ethical implications of modern developments in agricultural technologies. These should include primary agricultural production, bearing in mind the relationship between agriculture and the natural environment, the UN millennium development goals, such as the fight against world hunger, and the impact of changing agricultural methods on rural and urban communities.



STATEMENTS

1. Research Integrity
2. Clinical Trials Regulation
3. New genetic techniques

RESEARCH INTEGRITY

Earlier this year the EGE was asked to comment on the development of a code of conduct for research integrity for projects funded through horizon 2020. and has provided Points to Consider in its development to the Commission



The EGE recognised the importance of European Commission actions to promote the highest standards of scientific integrity in the research that is funded through its own programs.



- This code of practice could be slightly different from those addressing research integrity elsewhere as the large number of participants in most research projects sponsored by the Commission have both a multi-national character and they are from very different backgrounds.
- A way to make explicit the commitment of all partners to these standards could be to require adherence to a code of practice explicit in the contracts of the research projects.
- Codes of Practice for Scientific Research exist in many European countries and research institutions. They respond to the needs of particular disciplines, to the legal system of each country or to specific traditions.

- European funded projects are unusual in that they almost always involve many actors from a variety of institutions, including universities, research institutions, small and medium sized enterprises and large companies.
- These organisations have widely different cultures. Integrity in relation to the manner in which the research is conducted (and its results disseminated) may therefore be of even greater importance than for other forms of funding.
- Research in clinical environments often involves many different actors in different institutions who may not be aware of protocols or results from other groups

