EuroScience supports appeals to the EU Council of Ministers to reject amendments of the European Parliament that will be deleterious for research and eventually for health care and society.

The European Commission the EU Council and the European Parliament are currently debating a new General Data Protection Regulation. The Commission proposal clearly recognized that for scientific research, in particular health research, the most strict regime, saying basically data shall be anonymized or formal consent by all individuals has to be given, would have disastrous consequences. Ultimately these consequences have a negative impact on health care. The institutions and researchers involved in health research have developed powerful ethical regimes for such cases, and universities, research institutes as well as funding organizations enforce these rules vigorously. The European Parliament, however, has late last year, proposed amendments introducing again the most strict regime, obviously not aware of the consequences and of the ethical regimes in place in health research. Other amendments restricting international transfer of such data will impede significantly international research collaboration which again will have ultimately deleterious effect on health care. Of course, the problem is much wider: much very valuable social science research is in a rather similar position: high standards have been developed in case personal data have to be used.

The Wellcome Trust was one of the first to raise alarm, and many scientific organizations, particularly in health research, have associated themselves with these objections.

EuroScience strongly supports these appeals, and it, too, calls upon the Council of Ministers, to reject these amendments: they will have a negative impact on research and eventually on health care and society. Scientific organizations have solid safeguards in place that have demonstrated time and again their value to deal with personal data in an ethical and responsible way. Scientists, and as a grassroots science organization EuroScience is in close touch with them, behave fully in accordance with these standards. The upcoming EuroScience Open Forum ESOF in Copenhagen from 21-25 June 2014 will provide an opportunity we will not miss to engage in debates with politicians, including EP members, and of course scientists, media, business and the public on these serious issues.

Lauritz Holm-Nielsen, president
Peter Tindemans, secretary general