

European Epidemiology Federation

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## Rapid Response Committee: EU Data Protection Regulation at the EURO Epi 2012, Porto, Portugal

At the IEA European Congress in Porto the new EU regulation was debated on Friday September 7<sup>th</sup>, 2012. At the session the Italian Judge Giovanni Buttarelli was present and took part in a panel debate with epidemiologists from Germany, Italy, Portugal and Denmark. He has worked as the supervisor and advisor (EDPS) for the EU on legal issues related to data protection.

The discussion addressed the current draft of the regulation (July, 2012), but several changes are expected in the next version of the text. Most epidemiologists can live with the current draft version of the new text because its paragraph 83 provides a framework for us to use data generated for a different purpose in research. However, there is no guarantee that this exemption will remain in the final text.

Buttarelli's advice was to follow the process in EU closely and request a consultation with the office in Brussels working with the text. He confirmed they know nothing about epidemiology and need to get the basic principles explained. He also advised we should speak with one voice and for that reason we believe the IEA, through the European Epidemiological Federation, should take the initiative to write a joint statement on behalf of all epidemiologists (public health, clinical epidemiology, psychiatry, environmental medicine, occupational medicine, cancer epidemiology etc.).

He believed that the research and public health argument was well accepted and in the long run we may be able to get a legislation that favors scientific use of administrative data or research data collected for a different purpose. At present this is illegal as the starting point and research using these data has to work with exemption as those stated in Article 83. He also stressed that many of the local restrictions issued by local governments or organizations may well be illegal and contradict the harmonization principle of the EU.

In short the process is still ongoing, the next version may come in 2014 will take force in 2016. The European Federation still has work to do.

Jørn Olsen, Neil Pearce, Shah Ebrahim, Cesar Victora; Adele Seniori Costantini and Rodolfo Saracci as guest coeditors.

Paragraph 83 in the second draft version:

1. Within the limits of this Regulation, personal data may be processed for historical, statistical or scientific research purposes only if:
  - a. these purposes cannot be otherwise fulfilled by processing data which does not permit or not any longer permit the identification of the data subject;

- b. data enabling the attribution of information to an identified or identifiable data subject is kept separately from the other information as long as these purposes can be fulfilled in this manner.