



Lunch Debate on Data Protection and Health Research

*26 September 2013 – 12.30 to 2 pm
European Parliament, Brussels*

Proposed legislation for protecting personal data in the European Union has led to fundamental disagreement between different stakeholders and amongst Members of the European Parliament responsible for the legislative process. The [Draft Report](#) issued by MEP Jan Philipp Albrecht (Greens/EFA Group, Germany) on 16 January 2013 has stirred controversy that is delaying the adoption process.

[EURORDIS](#) and [EPIRARE](#) (the European Platform for Rare Disease Registries) are co-organising a Lunch Debate, hosted by [MEP Marielle Gallo](#) (EPP, France) on Data Protection and Health research, to take place at the Parliament in Brussels on 26 September 2013.

The Draft Report has raised serious concerns amongst different stakeholders, including patients, researchers, industry and health professionals, that some of the measures introduced would hinder health research in general and more specifically research on rare diseases. The low prevalence characteristic of rare disorders makes the pooling of information and the optimal use of limited data critical. It is feared for instance that rare disease patients' registries would be impossible to manage because of further obstacles to the exchange and utilisation of data that are already very scarce in this field.

In March 2013, EURORDIS issued a [Joint Statement](#), supported by relevant scientific learned societies, medical groups and patient organisations in Europe as well as in Australia, Canada, New Zealand and the USA. The Joint Statement urges Members of the European Parliament to ensure that the proposed new legal framework for the protection of personal data does not obstruct medical research. The Joint Statement calls for clarifying and strengthening specific provisions in order to establish a productive European health research framework while protecting personal data. EURORDIS followed up the Joint Statement with a [Question and Answer](#) document designed to help readers better understand the complex issues involved.

We welcome the proposal for a Regulation rather than a Directive because it is directly applicable in the national legislative frameworks and will not suffer different national interpretations leading to inequalities. We also welcome the new legislation as it will take into account the many advances in technologies in the fields of communications, medicine and bioinformatics.

The European rare diseases community hopes this legislation can move forward in a manner that strikes the right balance between the protection of personal data and the protection of medical research in the EU.

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