

## **Launch of mutual collaboration between the ERNs and the stakeholders from industry and patients' organisations**

*Possible areas of cooperation between the European Reference Networks and other stakeholders, such as registries or clinical trials, have been explored during the first meeting between members of the ERNs Working group on Legal & ethical issues and relations with Stakeholders (LES) and representatives of the industry and of patients' organisations which took place on 25th February in Brussels. This meeting represents a first step to analyse how industry may support the ERNs activity and how patients' organisations perspective can be taken on board, which issues are at stake, how to maximize opportunities, which safeguards to ensure transparency and avoid conflicts of interest are to be put in place.*

Relationships between the ERNs and industry were already the object of a statement<sup>1</sup> published by the Board of ERN Member States (BoMS) in November 2016 to guide the collaboration between ERNs and industry or private funders. A joint working group of ERN Coordinators and BoMS, the ERN "Working group on Legal & ethical issues and relations with Stakeholders (LES)", has been set up and is currently working on a new version of the guidance and other policy documents relating to conflicts of interests, for the benefit of all ERNs. At the same time, patients' organisations have a crucial role to help consolidate the ERNs, for instance through their involvement into research or in finding ways to promote the collaboration between companies and ERNs in a way that helps to avoid conflict of interest situations. To better understand the position of industry as well as patients' organisations, the Commission organised this meeting which gathered the ERN LES WG with industry representatives (morning session) and patients' organisations representatives (afternoon session).

All stakeholders welcomed the initiative and are willing to contribute. ERNs need a diversification of funding to support their activity, and mutual benefits may come from cooperation on clinical trials, for instance. The dialogue with industry showed a clear interest in further exploring ways of collaboration particularly in the fields of registries or clinical trials, and the need to test different business models, for instance by scaling up the best practices identified in some countries. The need of transparency has been clearly underlined by all parties involved, as well as the fact that industry cannot be part of the ERNs governance model. Patients' organisations underlined several aspects like how to ensure that the results of the collaboration with industry will meet public interest for instance in a new treatment, or how to ensure that the ERNs activities funded by the industry do really reflect patients' needs.

The meeting was a first step of a process to start identifying the fields of mutual interest and the modalities to put in place to shape the collaboration between stakeholders and the ERNs. Written contributions and future meetings are envisaged to continue the reflexion and concretize it.

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1 [https://ec.europa.eu/health/sites/health/files/ern/docs/statement\\_industry\\_conflict\\_of\\_interest\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ern/docs/statement_industry_conflict_of_interest_en.pdf)



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