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Authors' reply to Rare diseases in Romania – a response to 'Transposition and implementation of EU rare diseases policy in Eastern Europe'

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We read with great interest the response by Emilia Severin and we would like to thank her for the detailed overview of rare disease policy-making in Romania [1]. Indeed, for the past decade all Eastern European countries have made substantial progress in this field. Romania has been an example of effective multi-stakeholder rare disease collaboration at national level, with the Romanian national alliance for rare diseases playing a major role in these activities.

We would like to put stress on the methodology of our study and in particular on the definition and primary reference source used for the indicator of national plan/strategy for rare diseases [2]. Under our approach, a national plan/strategy for rare diseases has to be (1) formally adopted and (2) government-funded plan/strategy, (3) consisting of specific priorities. These three criteria – formal adoption, public funding, and specific priorities – are based on the EUROPLAN Project's 'Selecting indicators to evaluate the achievements of RD initiatives' [3]. The website of the Directorate-General for Health and Food Safety (DG SANTE) of the European Commission was searched for existing national plans for rare diseases in Eastern European countries. In fact, DG SANTE has established a detailed collection of rare disease documents on its Internet site in order to boost the dissemination and adoption of such policies. Under the Council's Recommendation on an action in the field of rare diseases, the European Commission required Member States to regularly report on rare disease policy progress, with this information usually published on the DG SANTE's rare disease web page [4]. As the official health policy directory of the European Union, DG SANTE is considered the most credible and up-to-date information source for rare disease policy activities in Europe.

In the case of Romania, our final conclusion was based on the following considerations. First, on DG SANTE's web page the data for Romania indicate 'Romanian National Plan for Rare Diseases 2010–2014 (Draft)' [4]. This information clearly shows that this policy document cannot be regarded as officially adopted by the Romanian Government. Furthermore, the hyperlink provided is no longer working and we could not assess the plan itself. RD-Action, as suggested by Emilia Severin's response as a reference source for the official European position on this issue, is a joint action, funded by the European Union's Health Programme 2014–2020. This is a project activity and its disclaimer states that its deliverables cannot

be considered to reflect the views of the European Commission and/or DG SANTE or any other body of the European Union [5].

Second and more importantly, we explored the official documents available on the web page of the Romanian Ministry of Health in order to check and better understand the current state of this draft plan. We found and analyzed Romania's National Health Strategy 2014–2020 [6]. Indeed, rare diseases are listed as a public health sub-priority in this document under Axis 3 (Prevention of non-communicable diseases), which is clearly stated in our published article ('Still, rare disease activities are included in the Romania's National Health Strategy 2014–2020, as a part of axis of prevention of non-communicable diseases' [2]). However, a sub-priority is not an equivalent to a formally adopted specific national plan for rare diseases. This is a part of an overall health strategy and such documents exist virtually in all jurisdictions in the world. Furthermore, chronic non-communicable diseases are now a universal health policy priority in all countries. Rare diseases do make part of this broad field. But it does not automatically mean that each country with a health strategy has a separate national plan to tackle rare diseases.

In conclusion, as we were not able to clearly identify a formally adopted specific document from Romania, entitled 'National plan for rare diseases', and Emilia Severin did not provide such references either, we believe the findings and recommendations of our study are correct and in accordance with the methodology presented.

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Declaration of interest

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