

EuropaBio Patients BioForum - Key Messages

Read the key recommendations of the EuropaBio Patients BioForum to the new EU institutions.

On 10 October 2019, the EuropaBio Patients BioForum met to discuss the policy and research prospects for healthcare biotechnology in the EU beyond 2020. EuropaBio member biopharmaceutical companies leading the way in medicine innovation in the EU and organisations representing EU patients from various disease areas, such as rare diseases, heart diseases and cancer, reviewed together the political developments in the wake of the EU elections and in anticipation of a new European Commission taking office by the end of the year. The patient and business community exchanged expectations for the impact of the new political set-up on the EU health programme and set together policy priorities for enabling healthcare biotechnology to deliver to EU patients.

The EuropaBio Patients BioForum:

- 1.** Supported the political guideline of the new European Commission to put forward Europe's Beating Cancer Plan and underscored that, rather than focusing all its resources in the health space solely on the mission for beating cancer, the Commission should reinforce its efforts for implementing the One Health approach and, notably, leave no disease areas unaddressed. The Patients BioForum also stressed the importance of stronger engagement by the Member States' EU Council Presidencies in the One Health approach.
- 2.** Noted the criticality of addressing the problem of many innovations reaching patients and healthcare professionals slowly or not reaching them at all. The patient access to biotech healthcare innovations which meet public health needs should guide all EU policies in health. Further, artificial intelligence should improve the accessibility of EU healthcare.
- 3.** Called for better coordination between the various directorate-generals of the new European Commission for achieving better implementation of the EU Health Programme. The recently established new DG on Structural Reforms should facilitate such improved collaboration.
- 4.** Put forward suggestions for improving the European Reference Networks (ERNs) after taking stock of their achievements at 2,5 years since the launch. Notably, the Patients BioForum suggested that efforts should be made towards improving the ERNs data structure by means of implementing artificial intelligence tools for better quality of the information, fit-for-purpose algorithms, and training the users of ERNs on utilising the accessed information, as well as towards the efficient implementation of the adopted guidelines for patient registries. Next, pathways should be defined for the integration of the ERNs into the national healthcare systems. Further, the

effectiveness of the ERNs should be monitored on a systematic basis. Last, but not least, the Patients BioForum asked that the ERNs Board of the Directors, the EU Member States and the European Commission create more opportunities for conversation with both patients and the healthcare industry.

5. Stressed the importance of providing high-quality social care to patients with rare diseases. It was suggested that scientists are involved in the training of social workers, so that they can cater better to the needs of patients with rare diseases.

6. Welcomed the efforts of the European Commission to involve patients in the assessment of projects submitted under the new EU research programme for innovation-led growth – Horizon Europe, towards achieving result-oriented spending on health-related objectives. Notably, for achieving better involvement of patient organisations in Horizon Europe, the Patients BioForum recommended that the European Commission uses the database of patient organisations of the European Medicines Agency.

The next meeting of the EuropaBio Patients BioForum is in spring 2020 under the topic “Embedding change” and will take stock of both the best practices and challenges resulting from the cooperation between healthcare authorities, researchers, patients, and industry.