

Brussels, 27 November 2020

Dear EU4Health Programme Triologue Negotiators,

The new standalone programme on health proposed by the European Commission earlier this year represents an important opportunity to build stronger, patient-centred, health systems that can provide care to all, under all circumstances.¹

The agreement negotiated between the European Parliament and the Council, seeing €5.1 billion allocated to the EU4Health programme is a very welcome accomplishment. This is an important recognition of the need to invest in Europe's health, responding to the expectations of European patients and citizens.^{2,3}

In the context of the ongoing Triologue negotiations on the EU4Health programme, we trust that the German Presidency, the European Parliament and the European Commission will achieve the best possible compromise and that ambition for the programme will be upheld.

Outlined below are three key elements of the Commission and Parliament's positions which we strongly support and which we believe are essential to an inclusive programme, ultimately benefitting patients and citizens in Europe.

1. An inclusive governance framework, with direct participation of patient organisations and civil society (article 16)

We believe that to achieve its objectives and to ensure efficient use of the assigned budget, the EU4Health programme should foresee a solid and inclusive governance framework to effectively manage and monitor the implementation of the programme and ensure its positive impact on European citizens and patients.⁴ Such a framework should facilitate transparent and evidence-based design of annual work plans that allow the programme's priorities to be in line with the needs and expectations of citizens and patients. To accomplish this, there is need for a clear and meaningful civil society role in the governance of the programme.

Meaningful patient involvement is currently an underused resource with real potential for improving the effectiveness, efficiency and long-term sustainability of healthcare systems, a key objective of the new health programme. Patients' organisations channel the voice of patients by representing their interests, helping policymakers understand the lived experience and enhancing the relevance of policymaking. No other stakeholder is as informed about patients' needs and priorities as patients' organisations.

¹<https://www.eu-patient.eu/globalassets/policy/statement---epf-proposes-progressive-patient-centred-eu4health-programme-15.09.2020.pdf>

²Europeans think the EU spends 13% of its budget on health, while in reality the figure is 0.05% – 260 times less. Almost half would like more EU budget to be allocated to health. <https://www.bruegel.org/2018/01/eu-budgetexpectations-vs-reality/>

³ EPF Elections Manifesto for the 2019 European elections, www.europeforpatients.eu

⁴<https://www.eu-patient.eu/globalassets/policy/statement---epf-proposes-progressive-patient-centred-eu4health-programme-15.09.2020.pdf>

We believe that the EU4Health Steering Board as proposed by the European Parliament will complement the expertise of the existing Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases, which is limited to representatives of the Member States. We believe that the Steering Board will ensure a clear and meaningful role for civil society and patients' organisations in the governance of the programme, facilitating coproduction and ensuring a concrete platform for civil society and patient involvement. Important precedents for this exist, if we look to the European Medicines Agency and the Innovative Medicines Initiative.

Furthermore, such a Steering Board with civil society involvement would also allow for better coordination of EU funding instruments, given that civil society in the field of health are involved in various instrument. As an illustration, if certain needs for further research are identified in the implementation of an EU4Health-funded project, this need should be highlighted to (for example) the Horizon Europe programme. Alternatively, if a pilot project is proven to have profound results, it could be scaled up with the help of structural funds, etc. The Steering Board, composed of stakeholders monitoring the different programmes from a health perspective will allow to achieve this type of input.

The COVID-19 crisis has highlighted, once again, that patients should be involved in shaping health policy at national and European levels, and why their unique knowledge and expertise, collectively and individually, are vital. The EU4Health programme represents a unique opportunity to act on this.⁵

We therefore ask negotiators to uphold the European Parliament proposal of an EU4Health Steering Board with participation of civil society.

2. Sustainable financing of patients' organisations and civil society through public funds (article 14, paragraph 1)

To enable European patients' organisations and civil society to play their legitimate and crucial role effectively and independently, coproduction should be built into all EU-level health-related initiatives along with sustainable resources for financial support to NGOs.

Despite the significant value that patients' organisations and their thousands of volunteers offer to individual patients and to society at the European level, they have limited or no access to public funding, resulting in dependency on donations by citizens and by the private sector. The current COVID-19 crisis has shown how vulnerable this financing is.

Furthermore, patients' organisations are increasingly invited to engage in policymaking at EU level, but without funding to support their crucial work. Patients' organisations and broader civil society will contribute to the implementation of the programme in many ways, such as through consultation, projects

⁵ <https://www.eu-patient.eu/globalassets/policy/statement---epf-proposes-progressive-patient-centred-eu4health-programme-15.09.2020.pdf>

or as experts. In addition, patients' organisations and broader civil society will also play an important role in monitoring and evaluation of the health programme and European legislation implementation. For this reason, the specificity of civil society and patients' organisations' contribution and role should be recognised and sustainably financed through public funds.

3. Direct grants should fund actions that are linked to the objectives of the EU4Health programme, as provided in annex 1 (article 14, paragraph 7)

For the reasons described above, EPF proposes the following compromise for article 14, paragraph 7: "Under the Programme, grants may be awarded without a call for proposals to fund the functioning of non-governmental bodies where financial support is necessary for the pursuit or implementation of one or more of the specific objectives of the Programme which have a clear Union added value as provided in annex 1, as long as those bodies fulfil all the following criteria:[...]"

In our view, European organisations contributing to the objectives of the programme should be eligible to benefit from such grants. Such grants are often the sole public source of funding open to European civil society organisations.

A programme which promotes and encourages strong civil society involvement will be welcomed by EU citizens, whose trust needs to be restored. Patient organisations are vital stakeholders in future policy discussions, and together with our 75 national and European members, we are fully committed to working with Member States and the EU institutions on defining a new and improved way forward.

On behalf of patient organisations and communities through Europe, representing more than 150 million patients living with chronic conditions, we count on you to consider our views in continued negotiations.

Thank you for your time and consideration.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Marco Greco', written in a cursive style.

Marco Greco
President
European Patients' Forum (EPF)

To: Mr Michael Clauss and Mr Ortwin Schulte of the German, Permanent Representation to the EU, Mr Cristian-Silviu Buşoi, Ms Sara Cerdas, Ms Kateřina Konečná, Ms Joanna Kopcińska, Ms Luisa Regimenti, Ms Michèle Rivasi, Mr Nicolae Ştefănuţă, Ms Véronique Trillet-Lenoir, Ms Chrysoula

Zacharopoulou of the European Parliament and Mr Matthew Hudson and Mr Stefan Schreck of DG SANTE, European Commission
Cc. Commissioner for Health Ms Stella Kyriakides

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The European Patients' Forum (EPF) is an umbrella organisation of patient organisations across Europe and across disease-areas. Our 75 members include disease-specific patient groups active at EU level and national coalitions of patients. www.eu-patient.eu