

STATEMENT

EPF proposes a progressive and patient-centred EU4HEALTH programme

15/09/2020

Amidst the ongoing COVID-19 crisis, attention has been turned towards enhanced European collaboration to ensure our health systems emerge from it stronger, more prepared and more people-centred. EPF believes this is a move in the right direction as health is not only a national matter – it is an urgent European and global health policy priority.¹

There are high expectations for the new EU4Health programme, which will be implemented as of January 2021. This leaves European institutions with little time to come to an agreement and to finalise the programme. In our view the new standalone programme on health proposed by the European Commission earlier this year represents an opportunity to build stronger, patient-centred, health systems that can provide care to all, under all circumstances. The programme also signifies a unique opportunity for a more robust European public health policy.

With the EU4Health programme, EPF strongly supports the increased investment in health at European level. This is an important recognition of the need to invest in Europe's health.² Further improvement towards a more patient-centred health programme as proposed by the European Parliament, is in EPF's view a very positive and promising step forward.³

We regret however the decision of the European Council to drastically cut funds from the EU4Health programme which undeniably implies an important setback for health at European level.⁴ It is regrettable in our view that Member States have not grasped the opportunity presented to collectively do more on health, delivering on expectations clearly voiced by citizens and patients.^{5,6}

Despite this disappointing setback, the EU4Health programme still represents a unique chance for enhanced European coordination to protect our health. We believe that ambition

¹ <https://www.eu-patient.eu/COVID-19/epf-covid-statements/epf-statement-on-the-covid-19-pandemic2/>

² <https://www.eu-patient.eu/globalassets/library/epf-statement--high-time-for-enhanced-european-coordination-and-competence-on-health.pdf>

³ [https://oeil.secure.europarl.europa.eu/oeil/popups/ficheprocedure.do?reference=2020/0102\(COD\)&l=en](https://oeil.secure.europarl.europa.eu/oeil/popups/ficheprocedure.do?reference=2020/0102(COD)&l=en)

⁴ <https://eu4health.eu/eu-health-organisations-react-to-cuts-in-eu-health-programme/>

⁵ Europeans 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/>

⁶ EPF Elections Manifesto for the 2019 European elections, www.europeforpatients.eu

for the programme must be upheld despite the significantly reduced budget compared to what was initially proposed.

EPF counts on the Council, Parliament and Commission to consider our proposals highlighted within this statement in continued negotiations. We invite policy makers to also consult EPF's complementary vision for the future of health in the EU, published in May⁷.

Delivering an ambitious and patient-centred EU4Health Programme

Europe needs a robust, forward-looking health programme which addresses not only cross-border health threats, but the formidable challenges posed by chronic diseases and persisting health inequalities that risk to be exacerbated by the current economic crisis.⁸

We suggest that policymakers develop clear proposals on how the programme budget will be spent and managed, while ensuring long-term investment in the strengthening of health systems and equal access to healthcare. Particular attention to the design and implementation of the programme is in our view paramount to effectively address not only the COVID-19 recovery but also boost the EU's preparedness for future cross-border health threats and strengthen national health systems in the long term.

The health programme should support the introduction of innovative solutions for better quality, more accessible, affordable and people-centred healthcare. Innovation should not only be about new products and technology for patients, but also about supporting research into and exchange of knowledge in social and systems innovation, such as participatory healthcare practices and health literacy initiatives.⁹

Solid governance and coordination for an efficient implementation of the EU4Health Programme

To achieve its objectives and to ensure efficient use of the assigned budget, the EU4Health programme should foresee a solid and inclusive, yet clear governance framework to effectively manage and monitor the implementation of the programme. Such a framework should also facilitate transparent and evidence-based design of yearly work plans.

How complementarity and operational synergies will be ensured with other Union programmes, while considering both 'health in all policies' and 'one health' approaches, remains to be further clarified in our view. Designed effectively, the health programme can be the engine to identify health research needs, but also translate health research into workable evidence-based policy.

⁷ <https://www.eu-patient.eu/globalassets/library/epf-statement--high-time-for-enhanced-european-coordination-and-competence-on-health.pdf>

⁸ Ibid

⁹ Ibid

Promoting synergies between European and national health resources to ensure long term effectiveness and sustainability of the actions themselves, in our view, also requires serious thought, consultation and coordination. We believe that the programme proposal should be strengthened in this regard.

This programme should also support national reform processes and the implementation of the country-specific recommendations on health addressed to Member States in the European Semester cycle. EU4Health funding should be allocated to actions that will support the implementation of the health-related country-specific recommendations and reforms. We believe that Member States should be required to use a part of the funding that is available to them under this new programme for the implementation of these recommendations.

We call for the inclusion of a clear and meaningful role for civil society in the governance of the programme.

The role and contribution of patients' organisations and civil society should be recognised and sustainably financed through public funds

Meaningful patient involvement is an underused resource with real potential for improving the effectiveness, efficiency and long-term sustainability of healthcare systems¹⁰, a key objective of the new health programme. Patients' organisations, together with other civil society health organisations, are an essential resource in shaping health policy at national and European levels. Patients' organisations channel the voice of patients by representing their interests, helping policymakers understand the lived experience and enhancing the relevance of policymaking. They also provide services, education, information and capacity-building.¹¹ Patients' organisations have access to the collective intelligence of patients in their community, helping identify patient needs and best possible outcomes, both clinical and non-clinical such as quality of life. No other stakeholder is as informed about patient needs and priorities as patients' organisations.

Patients' organisations and the wider civil society must be fully involved in shaping the future of EU health policy and research to ensure that the needs of the populations they represent are met and that their voices are heard and considered. To enable them to play this 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, in most countries and at the European level, they

¹⁰ The international evidence-base is quickly accumulating. For a recent recap see the report from EPF Congress 2019, "Meaningful patient involvement: a path to more effective health systems" available at <https://www.eupatient.eu/globalassets/events/epfcongressreport.pdf>

¹¹ EPF, Report - The Added Value of Patient Organisations, https://www.eupatient.eu/globalassets/library/publications/epf_added_value_report_final.pdf

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.¹² Furthermore, patients' organisations are increasingly invited to engage in policymaking at national and EU levels, 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 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.

EPF proposes that the Commission's multi-year funding rules¹³ (currently covering the years 2018-2021) be re-examined to ensure a more inclusive approach to grant application and enhanced opportunities for civil society and patients' organisations.

Such a programme which promotes strong civil society involvement will no doubt be welcomed by EU citizens, whose trust needs to be restored. Patient organisations are vital stakeholders in future policy discussions, and EPF is fully committed to working with the EU institutions on defining a new and improved way forward.

ABOUT EPF:

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

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¹² <https://www.eu-patient.eu/globalassets/images/epf-letter-to-commissioner-kyriakides-27-march-2020.pdf>

¹³ European Commission, 3rd Health Programme - Operating Grants Forms and proposal templates, 2014
https://ec.europa.eu/research/participants/data/ref/other_eu_prog/hp/hp-call-pt-fpa-sga-og_en.pdf