

EPF Statement in Response to the Written Consultation on the WHO European Programme of Work

18 July 2020

Three core priorities of the EPW

The European Patients' Forum welcomes this ambitious and timely draft programme of work. Its determination to address health inequalities and to leave no one behind aligns well with the UN SDG3 on health. We consider that the empowerment and meaningful involvement of patients and communities – i.e., the people the health systems aim to serve – at all levels will be critical to the shaping and the delivery of the EPW, but is not really elaborated in the document.

We wish to underline the critical importance of ensuring alignment between the EPW and the European Commission's policy priorities in health. The COVID-19 crisis has shown the need to deepen cooperation, not only at EU level but also between the EU Institutions and the WHO European Regional Office. Joint leadership and action is needed to tackle the structural weakness of our health systems.

Below, we comment on each of the three priorities. Recognising that the priorities are interconnected, some of our comments apply across the priorities.

1. Moving towards universal health coverage

The first priority includes several important priorities of the patient community. We welcome the objective of **improving integration of care** both vertically (between care levels) and horizontally (between health and social care). This has long been an important concern of patients with chronic conditions.¹

Investment in health and ensuring universal health coverage are political choices. Public investment in health varies greatly across the region, but the COVID-19 crisis has exposed under-investments in health and social care even in wealthy European countries. A society that values health and makes it a political priority must ensure sustainable investment in health, including care, health promotion and prevention, as called for in EPF's Roadmap on Universal Health Coverage.² We are pleased that the EPW foresees dialogues with countries towards reprioritisation of budgets and ring-fencing of health and social care budgets, as well as reinforcing the capacity of national health authorities to engage in economic recovery plans.

Access to high-quality care based on need and without financial hardship is at the core of equitable health systems. Patient organisations have long been calling attention to gaps in health systems' capacity to provide truly universal coverage for all, as well as disparities in the quality of care. Out-of-pocket payments have been shown to contribute to financial hardship when there is inadequate financial protection in place, leading to reduced access to healthcare, worsening of health status, deepening poverty, and increased inequalities. There are evidence-based policy options available to

¹ <https://www.eu-patient.eu/globalassets/policy/chronic-disease/epf-chronic-diseases-consultation-response-2012.pdf>

² <https://www.eu-patient.eu/whatwedo/campaign/access-to-healthcare/epf-roadmap-to-achieving-universal-health-coverage-for-all-by-2030/>

reduce financial hardship and protect vulnerable people. EPF would like to see inclusion in the EWP of actions towards implementation of the 2018 WHO recommendations.³

There is a **need for more accurate data on gaps in universal health coverage** disaggregated by various factors including socio-economic determinants, in order to truly capture people's experiences of access barriers in different countries. To this end we would welcome an extension and deepening of the above-mentioned study. Patients living with chronic diseases are a specific vulnerable group whose perspectives should be explicitly included.

On medicines and medical supplies, EPF supports strong action towards **transparency in pharmaceuticals** and discussions on what may be a "fair" price for valuable innovation. To identify unmet needs accurately and develop innovation that brings added value, patient involvement in the development of medicines (and devices) needs to start from the shaping of research priorities and definition of unmet needs.⁴

EPF welcomes the focus on **person- and people-centred care**. However, we point out that significant efforts are needed to change policy and practice. While the value of patient-centredness⁵ is recognised in theory, and increasingly at political level, the patient community was disappointed to witness the almost complete side-lining of even statutory commitments to patient and public involvement during the COVID-19 crisis.⁶ The crisis proved that despite rhetoric, patient-centredness is not yet truly embedded in healthcare and is still regarded as "nice to have" rather than one of the essential elements of healthcare quality. Patient-centredness includes empowerment and their involvement, not only in their own care but also as partners in policy and practice change at organisational and systems levels.⁷

Patient involvement in training of health professionals is an emerging area with potential to shift the skill-sets and mindsets of future but also currently practising professionals. Recent research showed that educational institutions seek patients' input in order to teach more patient-centred and interprofessional care, for reasons of social accountability, and to make education engaging, powerful and transformative.⁸ The EPW action on health workforce mentions a "supranational consortium to develop in-service training programmes to reorient and requalify existing workforce towards people-centred care in post-COVID-19 context"; this offers in our view an invaluable opportunity to include the added value of patients' expertise.

Priority 1 includes two *flagship initiatives*, on mental health and empowerment through digital health.

As a cross-disease patient organisation, EPF welcomes the inclusion of a **flagship initiative on mental health**. Mental health is both an important health priority in itself, as well as intricately connected to many chronic somatic conditions. We welcome the focus on stigma, discrimination and social exclusion, mental health literacy, and the ambition to transform societal attitudes about mental

³ WHO Regional Office for Europe (2018) *Can people afford to pay for health care?* www.euro.who.int/en/health-topics/Health-systems/health-systems-financing/universal-health-coverage-financial-protection

⁴ For more details see EPF (2020) position paper on Pricing and value of innovative medicines, available at <https://www.eu-patient.eu/globalassets/documents/position-paper---pricing---finalversion.pdf>

⁵ EPF uses the terms patient-centred, person-centred and people-centred care, depending on context. The concepts are similar in their essential elements and philosophy regarding empowerment and involvement.

⁶ Richards T, (2020) "Patient and public involvement in covid-19 policy making". *BMJ* 2020; 370 doi: <https://doi.org/10.1136/bmj.m2575> (Published 01 July 2020)

⁷ EPF (2017) *Toolkit on Patient Empowerment*, available at <https://www.eu-patient.eu/globalassets/library/publications/patient-empowerment---toolkit.pdf>; *The Patient's Charter on Patient Empowerment* (2015), available at https://www.eu-patient.eu/globalassets/campaign-patient-empowerment/charter/epf_charter_pe_2016.pdf

⁸ Report of a joint EPF-BMJ session "Patients as teachers: what can professionals learn from patients?" at the 2019 EPF Congress, Advancing meaningful patient involvement – a path to more effective health systems. Available at <https://www.eu-patient.eu/globalassets/events/epfcongressreport.pdf>

health and service reforms. It will be critical for success of this Coalition to include diverse representation of patients from the mental health arena through involvement of relevant patient organisations.

The second **flagship initiative on empowerment through digital health** is very timely. The COVID-19 pandemic brought an urgent need for effective digital tools, and an unprecedented rush to implement eHealth services, including telemedicine consultations, in countries across the world. Patient advocates have welcomed this as something that should have happened a long time ago; nevertheless there are risks involved, for example in terms of eroding the quality of care and the human aspects of care, and undermining fundamental rights. There has to our knowledge not been any systematic initiative to evaluate these solutions to see if they really bring added value from the perspective of patients and professionals. EPF therefore warmly welcomes the foreseen review “of the use, gaps and efficacy of digital health solutions deployed in response to the COVID-19 crisis”, which should provide clarity on what solutions should be retained and scaled up. Digitalisation can potentially make healthcare not only safer and more efficient, but also more participatory.⁹ **The perspective of patients should be at the core of the flagship initiative** including the European Roadmap for Digitalization of Health Systems and the Charter of European values, principles and methods for health data access, management, governance and use.

2. Protecting against health emergencies

The COVID-19 pandemic showed that even advanced healthcare systems struggled to continue to provide care and treatment to patients in a crisis situation. Patients with chronic and sometimes life-threatening conditions were most affected. While cancer has received (deserved) attention¹⁰, we wish to stress that **the crisis touched on patients living with all kinds of chronic conditions**.¹¹ In many cases, communication was poor, and there was a lack of consideration to the situation of non-covid patients who were relying on timely access to care. Patients were not included in expert groups debating ethical guidelines for triage, for example.¹² Social distancing and isolation policies, too, have had particularly severe impact on people with chronic conditions, many of whom continue to self-isolate in fear of exposing themselves.¹³ The voices of those patients were largely unheard in policy decisions. In many cases, the disruptions they experienced in care continuity appear to have been the result of countries applying pre-existing pandemic plans.¹⁴ Clearly, those plans need to be re-evaluated to avoid repeating such unintended negative consequences in future. To ensure that health systems response measures to future crises are fit for purpose, it will be crucial to **involve communities of vulnerable people – including patients living with chronic diseases** – in developing those measures.

In our view it is moreover vital to include adequate representation of patients’ perspectives in the work of the **European Health Systems Foresight Group** given the importance of health systems becoming people-centred as well as equitable, sustainable and resilient.

⁹ <https://www.eu-patient.eu/News/News/patients-need-to-be-at-the-centre-of-digital-transformation-of-health-and-care/>

¹⁰ Wise J (2020) “Covid-19: Cancer mortality could rise at least 20% because of pandemic, study finds”, *BMJ* 2020; 369 doi: <https://doi.org/10.1136/bmj.m1735>

¹¹ EPF has published several statements on COVID-19 and is inviting patients’ experiences on an ongoing basis. See <https://www.eu-patient.eu/COVID-19/>

¹² Immonen K (2020) “The views of patients and the public should be included in policy responses to COVID-19”, *BMJ Opinion*, 30 March 2020. <https://blogs.bmj.com/bmj/2020/03/30/the-views-of-patients-and-the-public-should-be-included-in-policy-responses-to-covid-19/>

¹³ Giles C (2020) “The shielder’s dilemma”, *BMJ Opinion*, 17 June 2020. <https://blogs.bmj.com/bmj/2020/06/17/ceinwen-giles-the-shielders-dilemma/>

¹⁴ “How are countries reorganizing non-covid-19 health care service delivery?” Cross-country analysis by the European Observatory on Health Systems and Policies, 6 May 2020. <https://analysis.covid19healthsystem.org/index.php/2020/05/06/how-are-countries-reorganizing-non-covid-19-health-care-service-delivery/>

3. Promoting health and wellbeing

EPF is supportive of the WHO's ongoing work on public health, health promotion and prevention, the social determinants of health, strengthening primary care and health in all policies. Under the third priority, action areas 3 on *safer healthcare*; 4 on *strategic intelligence on levels and inequalities of health and well-being*; and the *flagship initiative on immunisation* are particularly relevant to EPF's ongoing work.

Safer health care

Patient safety is both a goal, i.e. a state of being that is free from harm; and a practice, i.e. the processes and structures that aim to make healthcare safer. Unsafe care undermines the goal of universal health coverage and erodes trust between the health system and its users. EPF is committed to advancing patient safety, particularly through the empowerment of patients and families. Having worked extensively in this area at EU level and with WHO in the past, we warmly welcomed the WHO resolution WHA72.6 of 2019 on patient safety and the creation of the official world patient safety day. We reiterate that the WHO resolution specifically calls for engaging patients and families and would like to see this aspect addressed in the EPW also. The important opportunities of improving safety through meaningful engagement of patients and their families in healthcare environments should not be missed in the EPW.¹⁵

Strategic intelligence on levels and inequalities of health and well-being

Existing measures on access to and quality of care do not adequately capture all barriers to healthcare and related inequalities. EPF thus supports the development of better metrics; these should include patient-reported and co-developed measures, should encompass both outcomes as experiences, and should capture the perspectives of underserved and marginalised groups of people.

The Immunisation 2030 agenda.

Equitable access to vaccination throughout life is an element of universal health coverage. The current COVID-19 pandemic has made this priority more urgent, while the picture is complicated by the rise in hesitancy and misinformation about vaccines and eroding public trust. Infectious diseases are particularly dangerous for people living with chronic conditions, and vaccination may not be straightforward or even possible for some, such as immunocompromised people. EPF has focused in recent years on highlighting the importance of access to vaccination for patients with chronic diseases, as well as reliable, comprehensive and patient-relevant information about immunisation. We would like to see these perspectives reflected also in the 2030 WHO immunisation agenda.

Three tracks to maximise country impact

The tracks and actions outlined seem comprehensive in themselves. However, the **involvement of civil society** is in our view not adequately accounted for. A strong and diverse civil society is a vital force in democratic societies. It is important to involve civil society organisations in strengthening national health systems and reinforcing their accountability, transparency and legitimacy. The EPW stresses the need to reinforce leadership capabilities of health authorities in the region and challenges related to low public confidence and trust coupled by high expectations in many member states. Trust issues is also connected to the spread of misinformation via different channels exacerbated by the COVID-19 pandemic.

¹⁵ For more on patient and family empowerment for safer healthcare, see: <https://www.eu-patient.eu/whatwedo/Policy/Patients-Safety/>

We stress the need to implement best practices in **transparency** and **accountability** that are required to reinforce, or in some cases, reinstate, the legitimacy of public institutions and public trust. Transparency, good two-way communication, and health literacy-friendly practices are also key to raising the overall health literacy of the population and making the health system more easily “navigable”.

Under Q3 we outlined specific areas where patient involvement – and, depending on the topic and context, wider community and civil society involvement – will be critical to achieve policies and actions that bring real added value and take health systems concretely towards the goals of being people-centred. In addition, there is a need to **encourage concrete actions and share good practices** of meaningful (non-tokenistic) involvement – for example on structures, mechanisms, values, communication and evaluation – are developed with the involvement of patient and civil society organisations, and used to build countries’ capacity at different levels.

Capacity, as well as mentality and political will, to involve patients and the public vary widely from country to country, as well as between sectors (e.g. health ministries, public health bodies, health technology assessment agencies, or regulatory agencies for medicines and medical devices). It may also be a question in some cases of changing policy-makers’ attitudes; the WHO’s recognised role as convener and facilitator is extremely important. See also the next question.

How the European Patients’ Forum can contribute to making the Regional Office collaborate more effectively and efficiently

EPF is committed to further discussions on how we and our pan-European membership can work in synergy. We have a community of 75 member patient organisations across the European Union, representing both national coalitions of patients and disease-specific patient organisations; and a wider network of patient advocate contacts beyond the Union. EPF’s statutes now cover the wider European region beyond the EU. As we will be taking steps towards engagement with the patient communities in the **Western Balkan countries** particularly in the next years, we look forward to discussing with you how our joint efforts can contribute to the strengthening of the patient organisations there as a vital part of civil society and create long-lasting relationships with them.

EPF has extensive expertise and experience in bringing the patient perspective on healthcare access, equity, quality and safety, patient empowerment and involvement, experience of working with the relevant EU legislative frameworks and in international collaborations with WHO and the OECD. We are happy to discuss how best to incorporate patient representation in various activities, in line with our priorities as outlined in our Strategic Plan and annual work plans.