

## Supplementary statement to the public consultation on EU funds in the area of investment, research & innovation, SMEs and single market

This statement complements the answers given to the questionnaire and provides additional information and commentary.

### **A stand-alone health programme is needed to support social cohesion, well-being and alleviate health inequalities**

It is EPF's strong belief, and that of our membership, that health should not be considered only as an instrumental value supporting economic growth. The evidence shows this is the case, but health is also a public good and a fundamental right. Timely, equitable access to appropriate, patient-centred care is an investment in society and in people's wellbeing. Thus EU policy on health should not be guided only by economic imperatives nor relegated to being an aspect of the Single Market. It should be treated as a policy objective in its own right, and EU policy should be based on the common values of universality, access to good quality care, equity and solidarity agreed by Member States in 2006.

EPF calls for an ambitious EU health policy, responding to the needs of citizens. The EU has a health competence and a responsibility towards European patients to take action and support Member States. We note that the letter of Mr Juncker of 1 March 2018 to Commission leaders includes the option of having a separate health programme as part of an "investing in people" cluster. EPF strongly believes this is a necessity in order to ensure policy coherence, leadership and thus effectiveness of future European health collaboration.

The challenges of chronic disease, cross-border health threats, and implementing the UN SDGs fully justify the existence of a stand-alone, well-resourced health programme under strong leadership. Such a programme must be appropriately funded, possibly even increasing its funding from the current level. Its objectives should reflect the priorities of European patients and citizens, as well as having broad impact beyond one country or one disease-area. The latter is important to avoid a deepening of the existing health inequalities across the EU which undermine social cohesion and economic development. Complementing national policy is important, but future EU action on health should not merely reflect or reiterate national policies; it should also trigger actions that can promote better health, higher quality care, increase health systems' sustainability, support patient-centred innovation, and empower patients and citizens.

### **Key health system challenges call for collaborative European action and leadership**

Ensuring the sustainability of future health systems is key to realising the Europe 2020 goals of smart and inclusive growth. Chronic diseases account for up to 80% of healthcare costs in terms of premature deaths, healthy life years, and lost productivity. Chronic illness impacts negatively on patients' quality of life, education and employment. Multimorbidity is rapidly increasing, which leads to specific challenges for patients as well as for healthcare systems in terms of care delivery and organisation into new patient-centred care models and shifting towards more care in the community.

These challenges also include the legitimate expectations of patients that health systems must become more patient-centred. They are formidable to tackle and cannot be solved by Member States in isolation. They therefore call for appropriate investment and coordinated action both at national and EU levels. In this area the EU can provide high “added value” by complementing and supporting Member State efforts and bringing coherence to a fragmented area of policy and practice.

Below, we outline in more detail a number of specific policy areas where in our view EU action could provide high added value and directly benefit European citizens – a large proportion of whom are either living with chronic disease themselves or are family members of patients, or informal carers.

### **Patient Empowerment and health literacy**

The need for patient-centredness to be embedded in health systems through patient empowerment is recognised in the Regulation setting up the third Health Programme: “Healthcare practices should be informed by feedback from, and communication with, patients.” The current EU Health Programme recognises the centrality of the patient perspective in health policy; stating that “Patients need to be empowered, inter alia by enhancing health literacy, .... The transparency of healthcare activities .... information to patients should be optimised. Healthcare practices should be informed by ... patients.” Patient-centredness is recognised as a core component of quality care, and evidence accumulates on its potential to improve patient experiences and outcomes, access and cost-effectiveness. In the final report of the chronic disease reflection process (2013) and other relevant work including the Expert Group on HSPA and the Joint Action on patient safety and quality (PaSQ), patient empowerment was identified as a key priority. Several studies were commissioned and concluded between 2014 and 2017.

However, their recommendations, notably that of EMPATHIE to develop an EU strategy on patient empowerment, have not been followed up. Despite the fact that there is potentially high EU added-value in having a coherent strategy at European level to support Member States and thus help alleviate inequalities and raise the bar on quality and efficiency of healthcare, no strategy has been developed. An EU strategy on patient empowerment followed by specific policy actions is in our view indispensable to ensure that this element is not dismissed or overlooked, and that the valuable but somewhat fragmented work done until now is fully exploited and built on. There are also important synergies with the new OECD initiative on healthcare quality indicators, which should be exploited fully. A high EU added value would be ensured by going beyond fragmented initiatives in single disease-areas or country settings, and supporting the effectiveness, efficiency and sustainability of health systems across the continuum of health promotion, prevention, self-management and chronic disease care.

### **Health literacy**

Health literacy is a specific aspect of empowerment, which includes health information. Health information is currently addressed through the prism of data collection to inform policy-making; this is important but equally and increasingly important is the converse: the need of citizens – including patients and carers – to have sound health information and develop their health literacy in order to make informed choices in an increasingly complex healthcare environment. Good, understandable information is necessary to support people's capacity to manage their health, maintain good health and manage well with a chronic condition, as well as navigate the health system and claim their legitimate rights. Well-informed, health-literate patients have been shown to be more discerning about their health, in a position to make more informed choices and decisions, and more likely to seek earlier diagnosis and recover faster. The converse is also true.

The current health programme states that the “transparency of healthcare activities and systems and the availability of reliable, independent and user-friendly information to patients should be optimised.” Specifically, the 2014 Council Conclusions asked Member States and Commission to consider presenting a proposal for a Council Recommendation on the provision of information to patients on patient safety; this has not happened. It would support the implementation of Directive 2011/24/EU on the application of patients’ rights in cross-border healthcare, which obliges Member States to provide accessible and understandable information about safety and quality of care, but has been poorly implemented to date as evidenced by patient feedback.

### **Access to safe, high-quality healthcare**

Persistent inequities undermine the European Union’s fundamental values, as well as its potential for better social cohesion and growth. The recent Reflection Paper on the Social Dimension of Europe noted that half a million premature deaths could be avoided, not only by better prevention but also by more timely and effective healthcare. Chronic disease is recognised as a risk factor for health inequalities.

The EU has committed itself to implementing the UN Sustainable Development Goals, of which Goal 3 focuses on health, including access to medicines and healthcare. Currently, however, there is no EU-wide methodology or proper indicators to monitor access to healthcare. The EU could add value in the area of tackling health inequalities inter alia by developing a framework for monitoring access gaps, benchmarking access with patient-centred indicators, and supporting implementation of good practices. Within the “Health at a glance” initiative, meaningful feedback from health stakeholders such as patients’ and healthcare professionals’ organisations should be sought to achieve a reliable benchmarking framework for access and to give direction for future EU actions.

### **Patient safety**

Patient safety is a specific issue within wider healthcare quality that touches potentially all European citizens. A 2016 EU study estimated the direct costs of unsafe care to be around €25 billion and an OECD 2017 study showed over 10% of hospital budgets are spent on correcting preventable errors. The Commission communication on effective, accessible and resilient health systems (2014) pointed to further action to improve safety and to reduce unwarranted variation between and within Member States; there was strong support in the public consultation in developing a broader EU agenda to address quality and safety of healthcare. Nevertheless, the sustainable collaboration framework called for in the 2014 Council conclusions has not materialised, despite clear messages from EU Institutions including several European Parliament resolutions and the public consultation calling for more collaboration at EU level.

Improving safety – for example tackling healthcare-associated infections and antibiotic resistance – requires effective cross-border collaboration and can provide high EU added-value as well as direct benefits to citizens. It has been shown by the valuation of previous health programmes that they have been successful in promoting such issues on the agendas of the EU and member states, thus helping sustain a longer term vision in the face of immediate political distractions. Member states cannot effectively tackle this issue alone, and the cost of non-action – to patients, citizens and society – is likely to far exceed the cost of action in the long term.

### **Innovation for the benefit of patients**

Innovation is crucial to improve health and the efficiency of healthcare as well as enhancing Europe’s competitiveness and growth. Disruptive technology, e.g. digital tools, can bring solutions to patient-

centred health care delivery, with shared electronic health records and self-monitoring tools already blurring traditional distinctions between clinical and self-care.

Many digital health projects are currently being funded both under the Health Programme and H2020. In line with our reply to the public consultation on the Transformation of Health and Care in the Digital Single Market, we support patient involvement in development of (new) technologies, while keeping accessibility and affordability as objectives and ensuring uptake by making sure patients have access to their data and can consent on the reuse of their data in an informed manner.

The recent Mid Term Review of the Digital Single Market pinpointed the need for a coordinated, coherent policy vision on digital health and care innovation, and a Commission Communication on digital health is forthcoming. For Digital health to result in tangible added value for patients and citizens, innovation needs to be needs-oriented and embedded in health policy, rather than treating healthcare as a side issue in a technology-led process.

### **European-level organisations in Joint Actions**

The proportion of Joint Actions compared to projects has increased steadily since 2014, with the 2017 work programme being almost exclusively JAs. We are concerned that changes in the rules governing JAs have undermined the participation of European-level stakeholder groups, such as patient NGOs. As the only way for a stakeholder group to be an associate member is to be endorsed by a Member State – which can only endorse limited number of groups – EU stakeholders now have very limited capacity to be involved in decision-making or implementation of JAs. Coupled with lack of funding for NGOs within JAs, this severely restricts their contribution and undermines the impact of JAs. The lack of transparency in the shaping of JAs and lack of stakeholder involvement are in our view a dangerous shift away from inclusiveness in implementation of the HP, undermining efforts made over past years to promote participation. Procedures for granting JAs should be reviewed to ensure effective and transparent access for European NGOs representing stakeholder groups directly concerned by the actions.