Elections Manifesto 2019

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Putting What Matters to Patients at the Heart of EU Health Policy

Foreword

In 2019, European citizens will vote to elect a new European Parliament. Shortly after, a new European Commission will be nominated. This change takes place in a challenging political environment that has included the possibility of less or no meaningful EU action on health post-2020.

This is not what patients want. Patients are political actors and stakeholders in health policy, with a large proportion of Europeans living with one or more chronic diseases. Europeans care about health as an EU priority: 70% of citizens want “more EU in health and more health in the EU”.

Patients see and feel the benefits from having a strong, co-ordinated European health policy and political leadership and support. Patients’ advocacy in the European elections is crucial to drive positive change. The European Patients’ Forum, as the EU-level organisation representing the voices of around 150 million patients living with chronic conditions, wants new and old policy-makers to actively listen to and act on patients’ priorities in all policies that have an impact on patients’ lives.

EPF therefore calls on the political leaders of the EU, Members of the European Parliament and the future Commission, to ensure health is an EU policy priority and that patients’ rights are implemented across the EU, by taking concrete action on the issues that our members say matter most to patients:

1. Accessing the healthcare we need with no discrimination

The EU should act to ensure that all patients, everywhere in the EU, have affordable, timely access to the spectrum of healthcare they need, from diagnosis to treatment, social and other support services.

The EU should also act to eliminate all forms of discrimination, including discrimination encountered by patients in healthcare environments and in everyday life. Equitable access boosts growth and contributes to a society that is prosperous, productive, inclusive, and fair. Equitable access requires political and financial investment. It is also in itself an investment in the whole of society.

Healthier people contribute to economic growth and wealth. But even those who are not “healthy” have much to contribute to society. Patients are able to reach their individual potential for health and well-being when they have timely and affordable access to the full spectrum of care and services, based on need not means.

While fair treatment is a basic right, the current EU legislative framework does not cover discrimination on the grounds of health status. Yet patients with chronic conditions face various forms of discrimination and social stigma, including in healthcare, social services, education, employment and financial services.

2. Being empowered

The EU should adopt a new, comprehensive and up-to-date European legislation on patients’ rights.

All patients have the right to define their own goals and participate as equal partners in care. Only patients know what matters to them most in the management of their health condition. Patients want to live a normal life; and only each patient can define what “normality” means for them. Every patient across the EU deserves to benefit from empowering care practices and a culture of partnership, including shared decision-making and self-care support.

When patients are genuinely involved in healthcare decisions and their preferences are listened to and acted on, the result is better health outcomes, more engaged patients and even lower costs. But, despite recognition in policy documents and a fast accumulating evidence base, there is still no consistent approach in Europe to patient empowerment. Patients’ rights are to some extent addressed, but they are fragmented across different pieces of legislation and far from comprehensive.
Patient empowerment/person-centredness is recognised as a critical component of quality in healthcare. Different levels of empowerment depending on where you live are a specific inequality in the quality of care – a health inequality. The EU must address this by actively promoting patient empowerment so that all patients everywhere have care that is person-centred, high quality, and based on the same fundamental patients’ rights.

3. Driving the development of digital health

The EU should ensure that Europe’s future digital health tools and systems start from patients’ priorities and are co-developed with patients.

Digitalisation in healthcare should lead to better quality, safety and sustainability of care – but it also promises to transform care into a much more participatory process. Digital tools should start from the needs of healthcare users and be developed with the users, to ensure technology actually facilitates participatory, person-centred healthcare and leads to better outcomes for patients, and better value for society.

Digital health literacy is a prerequisite to increase empowerment and engagement of patients and citizens. Patients should have access to safe, high-quality digital information as well as tools, including shared health records developed with patients.

Patients are also the owners of their health data. They should be able to decide who to share it with, and on what conditions. This is currently far from the case. EU actions on new technological developments should always involve patients and patient organisations as true partners to ensure that patients benefit directly from sharing their data.

4. Being a partner in driving better research

The EU should involve patients meaningfully in all EU-funded projects and programmes, working with patient organisations to set ground rules for research involvement and compensating patients for their expertise.

Only this way can research be truly driven by patients’ real-life unmet needs and priorities, and patients can be equal partners in delivering high value, sustainable solutions.

Meaningful patient involvement in research is not only a moral imperative – because research directly impact patients’ lives – but also practical.

For example, the outcome measures selected for clinical trials must be those that matter most to patients in order to produce valuable innovation. More research should also be directed towards non-pharmacological approaches to care, such as patient-centred care models, and supporting the implementation of good practices.

Publicly funded research should be fully transparent on its results and data in order to reduce duplication and waste in research. Lay-friendly information on scientific research is needed to empower patients with knowledge, increase understanding of the benefits of scientific research and help counter the spread of anti-science and misinformation.

5. Helping make better health policy

The EU should ensure meaningful patient involvement in all parts of health systems, by working with the patient community to share learning and support the implementation of good practices.

To meet the challenges of chronic conditions, healthcare needs to become more person-centred and co-ordinated, rather than fragmented and disease-focused. For patients, ‘innovation’ means not only treatments, but also new and better ways to organise and deliver care. Empowered patients are partners in improving care quality, from self-management support through shared care planning to service evaluation and (re-)design.

Patients’ experience and expertise can help make better policy. Meaningful patient involvement is an underused resource in health innovation and health systems strengthening. It has real potential for improving the effectiveness, efficiency and long-term sustainability of healthcare systems.

Patient organisations contribute the unique perspective of patients. They should be represented in all health decision-making bodies, both at EU and national levels. The biggest barrier to patient involvement in health policy is that most patient organisations function with minimal budgets and voluntary staff. To enable them to play their policy role effectively, they need an “open door” but also ethical and sustainable financial support.
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About EPF

The European Patients’ Forum (EPF) is the EU-level umbrella organisation of patient organisations across Europe. Our members are chronic disease-specific patient groups at EU level and national coalitions of patients.

Our Vision is that all patients with chronic conditions in Europe have access to high-quality, patient-centred health and related care.

Our Mission is to be the collective influential patient voice in European health and related policies and a driving force to advance patient empowerment and equitable patient access to care in Europe.

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