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Patients group: 'Access to healthcare is a basic EU citizens' right'

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The European Parliament elections and the nomination of a new Commission next year offer a fresh opportunity for patients to encourage policymakers to commit to a healthier Europe, says Anders Olauson.

Anders Olauson is the president of the European Patients' Forum (EPF). He answered questions from EurActiv's Henriette Jacobsen.

Why is it necessary to launch a campaign on patients' rights to coincide with the European Parliament elections?

These elections are a big milestone for patients in Europe. The stakes are much higher than in 2009 - the political and economic agenda for patients, and indeed for all of us, has evolved much since then. We know from our 61 members [the EPF represents 61 patients' organisations] constituencies are facing are enormous. Fundamental inequalities and lack of access prevail, yet demand as our population ages, and becomes greater. We need to ask ourselves, what kind of society do we want, for us, and for the future -and health is absolutely central to this.

With our campaign, we want to create a sense of urgency and real imperative to address the roadblocks to patients' access to proper healthcare. Access to healthcare is a basic EU citizens' right - yet it is still not a reality for many of us, a situation made worst by the economic crisis. The European Parliament elections and new Commission 2014 offer a fresh opportunity for the European Patients' Movement to encourage politicians and policy-makers to commit to a healthier Europe as outlined in our Manifesto "Patients + Participation = Our Vote for a Healthier Europe"

You say in your campaign that you want to address the 'fundamental roadblocks to patients' access to proper healthcare' – what are these roadblocks?

In our campaign, we identify four fundamental roadblocks to patients' access to proper healthcare. By the lack of access, we are talking about a few things.

First of all, the fact that patients are still seen as the cost-drivers: on the contrary we are the ones who can help to guide decision-makers on how to offer good quality care that is also cost-effective. The reason is that we are "experts by experience" as we live with our condition every day, so we know what is most important to us and conversely, what services are not needed. This may not necessarily mean investing less, or more, but investing differently and more effectively.

Secondly, patients need to be empowered to be able to work in partnership with to be able to work in partnership with trusted health professionals (according to our individual

capacities and situation). Empowerment starts with high-quality information but also health literacy.

Thirdly, availability of the treatment as well as affordability is important. Healthcare is accessible to patients when it is functionally available to the patient who needs it, e.g. it is possible to get an appointment without undue delay and without having to travel far, and when the cost is affordable for the patient. Medicinal products are considered accessible when they are available in the market, can be prescribed and distributed through reachable channels, and the cost is affordable.

We also want to tackle discrimination faced by patients in health and faced by patients in health and social care as well as in domains like education and employment. Non-discrimination is one of the new goals we have clearly set in our new Strategic Plan for 2014-2020.

Finally, involvement when empowered, the policy-making should be designed more effectively around

healthcare and in research to develop new and better treatment. Sustainable healthcare must focus on quality – being patient-centred - rather than become a byword for cuts in healthcare budgets.

What can MEPs do to remove these roadblocks?

In our campaign, we ask European decision-makers to engage patients collectively and pro-actively through patient organisations in policy decision-making to ensure that all policies and practices reflect patients' real-life needs, preferences and capabilities.

Patient organisations are civil society NGOs that play an important role in the democratic process as proponents of patients' human rights. Patients act collectively through patient organisations to channel their expertise into decision-making most effectively. Although patient involvement is recognised as one of the shared operating principles of European health systems, there is still wide divergence across the EU in the recognition of patients as a legitimate stakeholder group and in the level of their collective involvement.

To enable them to undertake this vital role, EPF calls for concrete action to support the functioning of patient organisations through appropriate institutional, structural and financial support mechanisms at EU and member state levels.

The EU should adopt an EU strategy on patient empowerment, including an action plan on health literacy and high quality information for patients on all aspects of our care.

This strategy should include the identification and implementation of good practices in patient empowerment and involvement.

It should also include the development of practical tools to facilitate shared decision-making between patients and health professionals; identification and implementation of effective self-management interventions.

Moreover, there has to be a concrete strategy and action plan on health literacy and information to patients relating to all aspects of health, from health promotion and prevention through to therapeutic options and self-management of chronic disease.

There should also be research on the impact of patient involvement on quality of healthcare, patient satisfaction and cost-effectiveness as well as identification and sharing of good practices in integrated chronic disease management, both between primary and secondary healthcare providers, and between health and social care.

Finally it should support an EU initiative on equitable access to healthcare for all European citizens, through a multi-stakeholder platform.

You say that patients can be part of the solution to make health systems more effective, how?

Patients know what is most important to them and conversely, what services are not needed. This may not necessarily mean investing less, but investing differently and more effectively.

Patients are “experts by experience”. Their perspective on chronic disease is unique: patients live with the condition every day, learn to manage it themselves with support from healthcare professionals, and by necessity learn to navigate the health system in order to get the right care.

This is why patients should not be seen as passive recipients of services and benefits, but as active citizens and partners in chronic disease self-management. Patients need to be supported to be able to contribute to the sustainability of healthcare systems. However patient empowerment presents a challenge to the system and requires specific strategies, including embedding meaningful patient involvement at every level in the health system, thus supporting active patient participation in policy-making and the designing of care delivery systems.

Is the campaign more aimed at the MEPs than EU voters?

Through our campaign we want to remind decision-makers that we, as European citizens with chronic disease, are voters and that we want them to reflect a patients' perspective in their work.

The elections next year provide an opportunity for candidates to hear and listen to the patient voice and in so doing to help set the priorities for the new parliamentary session.

Whether or not decision-makers get the chance to listen depends on patients' and patient organisations' efforts to share their issues and concerns with them.

Therefore the campaign targets both decision-makers and voters and when we will cast our ballot; we will therefore be confident and feel good about voting for a healthier Europe, where patients are seen as a part of the solution for high-quality, sustainable and cost-effective healthcare.

As a starting point, we ask decision-makers and everyone who wants to be involved to fill in our [online form](#) so that we can keep track of patient-friendly people for further actions.

How will you involve patients (and health campaigners) in your campaign?

We shared some guidance and background papers with our members and allies on how to shape their own campaign based on ours and to promote the interests of the patients' community through their own networks.

Each patient organisation has unique needs and requires different approach to make the most of the 2014 EU Elections. Our guide aims to offer a framework with advice and core material to prepare the period ahead of the elections.

We encourage them to develop messaging and local activities that work for their own purpose, to reach as wide audience as possible. This is part of a general campaign to strive for including a patients' perspective into decision-makers' work.

What would you like the outcome of the elections to be?

We would like ensure that we have a large cross section of MEPs who are really committed to health and the patients' perspective and are ready to work with EPF on dossiers that affect patients and our families.

Another important outcome will be that patient' rights is part of the next Health Commissioner's portfolio.

An important by- product of the campaign is the enhanced awareness among patient communities across Europe that their vote, and indeed their voice, counts at EU level!