



EUROPEAN PATIENTS' RIGHTS DAY 2021

The role of civic society and Patients Advocacy Groups for more resilient Health Care Systems. Lessons learned toward a European Health Union

5th & 6th May 2021, from 10:00 to 12:00 CEST
Digital Conference

Final remarks 6th May 2021

Mariano Votta
Director Active Citizenship Network

Key messages and recommendations:

In my opinion, one of the main messages coming from this edition of the European Patients' Rights Day is that, in times of needed changes for more resilient healthcare systems, it is necessary to recognize the key role of Patients' Advocacy groups (PAGs), citizens' organizations involved in the field of healthcare and, more generally, all actors that promote health as a common good.

The second message is that, despite obvious difficulties, this is a propitious historical moment. First, Member States have just sent in their National Recovery Plans, where the issue of health is a key element. Second, in a few days the Conference on the Future of Europe will start and the hope is that health-related issues will be placed at the heart of the debate, as it will happen in the next Global Health Summit planned on May 21st in Rome.

By looking at the importance that will be given to health-related topics in this European political landscape, we will understand whether the necessity to create a stronger European Health Union, as underlined by the European Commission President Ursula von der Leyen, is merely a claim or the actual direction taken by the European institutions, and the key point with which we'll evaluate their work.

Overall, it is a time in which the institutions are called upon to listen to and involve the citizens. Will they be able to do this? At present, it does not seem so, and this raises our deepest concerns.

On the day that the Joint Declaration on the Conference of the Future of Europe was signed, the first results of the special Eurobarometer survey on the future of Europe were published. Among many other things, respondents were asked to choose what developments they want to see in Europe's future. Having comparable living standards (35%) and a stronger solidarity among Member States (30%) are the two developments most cited. Europeans also prioritise the development of a common health policy (25%). And for the citizens of nine countries, including Italy, health risks are a major concern.

At the end of April, Member States defined their Recovery Plan, a multi-year plan that will have a significant impact on future generations and all citizens, probably the main tool to guarantee more resilient Health Care Systems across Member States in the coming years.

If the aim of the Recovery Plan is the recovery and resilience of each of the countries in which we live, these are unattainable without the involvement of citizens in the choices and proposals the Plan contains, as well as in the monitoring of the projects

that will translate the Plan into concrete interventions. We demand that the Next Generation EU will be fully implemented, as this, among other indications, outlines - for the approval and implementation of each Recovery Plan- the need to involve social forces and the civil society. So far, this has occurred only in some countries, certainly not in Italy, and thus it is essential to ensure better transparency and participation so that, at least during its implementation, each Recovery Plan is monitored in its operational developments. Also, it would be good to be able to compare, country by country, the actions undertaken in terms of citizen's health.

Follow up and possible next step:

Therefore, we will try to do our part:

- On the one hand, by asking for an open government platform that enhances transparency and the monitoring of funds allocation. We have already started in Italy with an initiative called "Follow the Money" and thanks to our constituency we are now thinking about how we can leverage the work for other EU countries.
- On the other hand, by contributing to the work of the Conference on the Future of Europe, which will begin in 3 days on the occasion of Europe Day, through a cycle of ad hoc EU webinars that aim to put health-related issues at the heart of the debate.

In addition to these two initiatives, we will add a third one, which will actually be the first in chronological order, namely the production of a video message able to directly address the protagonists of the Global Health Summit. As you all know, global leaders and high-level experts will discuss how to improve health security, strengthen our health systems, and enhance the ability to deal with future crises in a spirit of solidarity. Their goal is to create a 'Rome Declaration' which includes principles that can constitute a powerful guide for medium to long-term structural changes. We would like to point out to them also what emerged in this XV Edition of the European

Patients' Rights Day, starting from the 10 Recommendations produced thanks to the contribution of more than 30 associations. Associations dealing with oncological and chronic patients underlined how, during the pandemic, these patients were left almost alone for several months, a situation that jeopardized 20 years of prevention. This cannot happen again. The same can be said regarding the attitudes of selfishness between and within nations. We hope that this will be taken into account by the European Institutions in the development of a "regulation of the European Parliament and of the Council on serious cross-border threats to health and repealing Decision No 1082/2013/EU"¹.

Finally, let me remind you that 2021 marks the first 20 years of activity of Active Citizenship Network. 20 years ago, my organization, Cittadinanzattiva, took the wise decision to start working not only at local and national level but also at European level. As our first advocacy tool, we immediately produced the European Charter of Patients' Rights, a milestone for those who advocate for health issues. Now, in the light of the situation we are facing, we will work on the drafting of a "Global Health Charter" from a citizen and patient perspective, to emphasize the interconnections - rights and duties - among all of us, close and far, patients and non, all equally exposed to serious cross-border threats to health, and all equally called, each for his role and function, to play an active role in support of the institutions and for the benefit of local communities and their constituencies.

- Finally, please let me remind you that this conference was kindly hosted by MEP Brando Benifei (S&D group) and MEP Tomislav Sokol (EPP group), and realized with

¹ EU Commission: "Serious cross-border health threats – stronger, more comprehensive rules": <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12795-Serious-cross-border-health-threats-stronger-more-comprehensive-rules>.

the support of Roche, Teva, Boehringer Ingelheim and Viatrix, which I would like to thank.

- At the same time, please let me thank our moderators Jennifer Baker, today, and Brian Maguire, yesterday, both journalists, and our media partners: “Health Europe” and the peer-reviewed journals “Advances in Health and Behavior” and “Family Medicine & Medical Science Research”.
- As always, thank you to the staff of ACN (Daniela, Bianca, Manuela, Elisa) and to our communication office.
- We will soon send out our newsletter, comprehensive of all the documents and outputs of this two-day conference.
- Thank you all again and stay safe. Goodbye from Rome.