

Towards A European Health Union: The Key Role of the Civil Society and Patients Advocacy Groups for More Resilient Health Care Systems

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ABSTRACT

The COVID-19 pandemic had a major impact on citizens' lives on several aspects. One of the most important has been the limited access to different health services. For Active Citizenship Network, the European branch of Cittadinanzattiva - a civic organization which promotes (since 1978 in Italy and since 2001 at EU level) citizens' activism for the protection of everyone's rights, maintaining the common good, and offering support to people in vulnerable conditions - it is not acceptable to respond to the immediate needs of citizens facing the Covid-19 pandemic simply by closing services. Instead, alternative organizational solutions are needed to guarantee continuity and quality.

Keywords: COVID-19, Health Care Systems, European Health Union

Our commitment is to engage citizens and citizens' associations across Europe to learn about and implement health policies. We believe it is fundamental, in this historical moment, to work to build a proper culture of engagement for citizen and patient organizations: learning and spreading good practices and lessons learned during the Covid-19 health crisis.

The pandemic has affected people's livelihoods, countries' economies, and international trade more generally. It has also exacerbated other systemic problems, from climate change to inequality. Yet, it has made one thing clear: we live in an era in which local problems quickly become global challenges. This means that we need to work together to recover from this crisis and to seize the opportunity to reconstruct, learning from our shared experience and ensuring that efficient and innovative tools and technologies become the basis for a more resilient, sustainable, healthy development.

Working at European level while living in Italy, I am perfectly aware of the urgent need to better address the consequences of the Covid-19 pandemic. Evidences collected during the crisis show that COVID-19 has had a significant impact on NCDs. Oncological and chronic patients have been left almost alone for months.

In Italy, according to the Italian Society of Cardiology, the fear of infection has tripled the mortality rate due to heart attacks. A situation confirmed also internationally by the European Society of Cardiology, that already in July 2020 denounced that the number of heart attack patients seeking urgent hospital care had dropped by

more than 50% during the first months of the Covid-19 pandemic. At the same time, new cancer diagnoses have been reduced by 52%. Data that risks throwing away 20 years of prevention.

To reduce the collateral damage caused by the pandemic, we confirm our convinced support and concrete involvement in initiatives aimed to:

- 1) affirm a life course approach to chronic disease prevention.
- 2) invest in telemedicine, digital health records as well as in digital health literacy.
- 3) simplify procedures, bureaucracy, and pathways for chronic and rare patients.
- 4) reinforce primary and continuity care outside the hospitals.
- 5) implement a new care model, for instance by considering the main insights put forward in the framework of the European Innovation Partnership on Active and Healthy Ageing.

All the key and open-minded actors active at global level agree about the need to strengthen the relationship between the public and private sector, to increase dialogue with the Institutions, and to involve academia, professionals, scientific societies, researchers, media in the dialogue.

As a citizen organization that works to reduce inequalities, protect patients' rights and promote civic participation in policy-making processes at all levels, we underline other three priorities or preconditions: a long term strategy instead of a single spot

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initiative; the need for an approach of "General Interest", because it is only by protecting the general interest that the particular interests are also supported; and, last but not least, the need to guarantee the protagonism of people, of the communities, of the intermediate bodies such as Patients' Advocacy groups, the citizens organizations involved in healthcare issues and, more in general, all the players that promote health as a common good. Right now, this is crucial to address the consequences of the Covid-19 outbreak properly.

As stated at the beginning of the Manifesto for a European Health Union: "This will not be the last pandemic. There will also be many other threats to health, including the effects of climate change, antimicrobial resistance, and much else. We cannot continue with life as before. We have to safeguard our societies but in ways that are proportionate to the dangers which threaten them. We must welcome the clear statement by the European Commission President Dr. Ursula von der Leyen in her September 2020 "State of the Union" address, setting out the necessity to create a stronger European Health Union (EHU), building on recent efforts by the European Commission to take action on cross border health threats".

This idea of facing the main challenges linked to the health emergency in a synergistic manner also lies at the basis of an important event that will take place in Italy: The World Health Summit, that will be held in Rome on May 21, 2021. It will discuss the actions taken to tackle the COVID-19 pandemic, access to vaccination and international cooperation.

Similarly, Active Citizenship Network is organizing the European conference of the XV European Patients' Rights Day planned on the 5 and 6 of May 2021 to value the good practices of citizen's engagement in health care policies and multi-stakeholder actions to tackle the pandemic for a future stronger European Health Union: starting from concrete examples and experiences coming from different countries, it will explore the point of view of patients' and civic associations, EU Institutions and experts, health professionals, as well as public and private bodies.

The event will provide a civic perspective, placing the citizens at the center of health care policies, not only as "users or consumers" of health services or "patients" with a specific disease, but also as active citizens participating in health policy making processes as essential stakeholders. This will strengthen our 'European citizenship', trying to reduce the gap between citizens and Institutions, by also showing the benefits that the EU could offer to patients.

Launched by Active Citizenship Network (www.activecitizenship.net), the European Patients' Rights Day (EPRD) was established on April 18, 2007 at the European Parliament to highlight a number of patients' rights, drafted in the European Charter of Patients' Rights, that should be recognized, respected and implemented all across Europe. Over the years, the EPRD has been included in the European political agenda. Also, thanks to ACN's constituency, the EPRD is celebrated every year at local, national and European level, and has become one of the main forums where to discuss the future of European healthcare and the crucial role of patients' rights for a more resilient EU.