

Final remarks

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We are grateful to have been involved in opportunities – like the Advisory Board in February and the today’s appointment - that allow leaders of civic organisations and Patient Advocacy Groups (PAGs) to share their needs, concerns, and best practices about prevention, management, treatment, and follow-up of COVID-19. This enables us to improve the current situation of care for patients with this disease, so thanks a lot to all the panellists and experts.

“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 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”¹. The 10 Policy Recommendations discussed today move precisely in this direction.

We, as representatives of the patient and civic associations present here today, who work to reduce inequalities, protect patients' rights and promote civic participation in decision-making processes at all levels, underline three priorities and preconditions necessary to strengthen the implementation of these Recommendations:

- ✓ a long-term strategy instead of a single spot 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 empowerment of people, communities, intermediate bodies such as Patients' Advocacy groups, citizens’ organizations involved in health issues and, more in general, all actors promoting health as a common good. Right now, it is crucial to properly address the consequences of the Covid-19 pandemic.

¹ Cfr. “Manifesto for a European Health Union”, <https://europeanhealthunion.eu/>

The Policy Recommendations want to be a contribute to the EU Institutions, taking into account that we all have responsibilities:

- 1) To **avoid the paradox effect for COVID-19 / LONG COVID-19 patients**: they risk experiencing the same situation as cancer and chronic patients, who were almost left alone during the first wave of the pandemic, with the risk to jeopardize 20 years of advancement in prevention and care. This risk, since the World Health Organisation officially declared the end of the health emergency, may increase.
- 2) To **support the HCPs categories**, living the so-called “medical deserts” phenomenon with related risks and paradox: on the one hand, we owe eternal gratitude to health workers for the sacrifice they have made, also in terms of human lives, in tackling the pandemic; and on the other, their legitimate demands have been almost ignored (or at least not considered a priority) in the countries of the European Union when allocating the National Recovery and Resilience Plans (NRRPs) funds for 'public health'. This is a discrepancy that citizens and patients are paying dearly for, seeing their right to access care restricted, whether it is highly specialised or routine, since the shortage of health professionals affects not only specialists but also GPs and paediatricians. Not to mention nurses and other socio-health workers.

The fact that sufficient and adequate measures were not taken in the elaboration of the National Recovery and Resilience Plans is a paradox that can hardly be justified. This aspect is strictly link with the following one:

- 3) To **reduce health inequalities**, a crucial factor especially to build trust among Eu citizen and EU Institution in front of the next European election in 2024.
- 4) To **recognize the key role of the civil Society and Patients Advocacy Groups for More Resilient Health Care Systems**. 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.
- 5) To **prioritize in public policy the value of the Health Literacy**, a very powerful individual and public health assurance tool that enables us to understand that health is a public good to be preserved through individual preventive actions that become more effective the more we follow them. As declared by experts², the COVID-19 infodemic (an excessive amount of information about a problem that is typically unreliable, spreads rapidly, and makes a solution more difficult

² Cfr. “COVID-19: health literacy is an underestimated problem”, www.ncbi.nlm.nih.gov/pmc/articles/PMC7156243/

to achieve) showed that low health literacy of a population is a globally underestimated public health problem. For example, in Europe³, nearly half of the adults reported having problems with health literacy and lacked relevant skills to take care of their health and the health of others. In this regard, the main question is still open: who is in charge of providing health literacy to the population? The health institutions? The health workers? The public schools? The PAGs? We await an answer from the politicians as soon as possible, at national level but also from the next class of politicians at European level, precisely because a poor level of health literacy would expose Europe, as a whole, to possible new health threats.

³ Cfr. "Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU)", www.ncbi.nlm.nih.gov/pmc/articles/PMC4668324/