


Save the Date
What are the challenges faced by COVID-19 high-risk patients and how can we improve their care?
An invitation-only roundtable discussion

24 May, 11:00-12:30
Stanhope Hotel, Brussels

This event will highlight the identified opportunities to achieve optimal care through the launch of Policy Recommendations on COVID-19 Patient Pathways.


These recommendations are the result of a collaborative effort between high-risk patient groups and key stakeholders. Join us to discuss the tangible actions that should be considered by European policymakers and Member States to tackle existing gaps.

The event will be held in person and by invitation only.

With support of 

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This event, funded by EFMD, is a non-promotional event, and thus, no specific products will be discussed.



Final remarks & Next steps

Mariano Votta

Director Active Citizenship Network

We are grateful to have been involved in opportunities – like the Advisory Board in February and the today' appointment - that allow leaders of civic organisations and Patient Advocacy Groups (PAGs) to better share their needs, concerns, and best practices in the 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 panelists 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. In coherence with this direction the 10 Policy Recommendations debated today are moving.

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 three priorities or preconditions needed to reinforce the implementation of the Recommendations:

- ✓ a long-term strategy instead of a single spot initiative;

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

- ✓ 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.

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 is, at least, true for Italy, the country I come from, which represents the nation that has benefited most in Europe from the NextGenerationEU funds, because it was the first and the most strongly affected by the pandemic on the European continent. Indeed, the reforms envisaged in the National Recovery and Resilience Plan will only have the desired effects if the investment in health facilities is accompanied by an adequate investment in the health workforce. 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 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. About it, is still pending the main question: who is in charge to provide health literacy to the population? Health Institutions? HCPs? The public school? The PAGs?

Potential next steps

Starting from tomorrow, I think that we need to move with the following steps:

- 1) Dissemination among our PAGs constituency with the possibility to show and explain to them methodology, reasons and value of the Covid-19 Patient Pathway Recommendations;
- 2) To widespread the Covid-19 Patient Pathway Recommendations through a social media communication campaign with the direct involvement of the PAGs;
- 3) To collect official endorsement to a broader spectrum of civic & patients' organizations across Europe;
- 4) To publish these Recommendations in a suitable article;
- 5) Within the year, to come back to Bruxelles but at the EU Parliament, for a Institutional policy dialogue meeting, in order to send a common request coming from several PAGs to the next

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

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

Parliament and next EU Commission: starting from the Recommendations, to require to the the MEP candidates their commitment on the topic after the EU election, if elected;

6) In a parallel way, in Member States, we need to identify tailored national recommendations.

Acknowledgements

As usual, at the end of any initiative, the list of acknowledgement is quite long.

Please, let me thank the PAGs involved in the Advisory Board, starting from the International and European umbrella organizations:

- International Patient Organisation for Primary Immunodeficiencies (IPOPI) and European Society for Immunodeficiencies (ESID). Together with them:
- Coalition of Healthcare Associations from Croatia (Koalicija udruga u zdravstvu-KUZ);
- National Association of Patient Organizations from Czech Republic (Národní asociace patientských organizací-NAPO);
- Cittadinanzattiva-Active Citizenship Network (ACN) from Italy but active also at the EU level;
- Council of Representatives of Lithuanian Patient Organizations from Lithuania (Lietuvos pacientų organizacijų atstovų taryb-LPOAT);
- Institute of Patient Rights and Health Education from Poland (Instytut Praw Pacjenta i Edukacji Zdrowotnej-IPPEZ);
- Federación Nacional de Asociaciones (ALCER) and Plataforma de Organización de Pacientes (POP) both from Spain.

Many thanks and congratulations to the RPP Group team, as well as to our moderator and journalist Mariam Zaidi.

Please let me remember that this event and the Advisory Board meeting was organised with the financial support of Pfizer.