

Therapeutic adherence during the COVID-19 pandemic across Europe: impact, experiences and perspectives from PAGs & relevant stakeholders

WEBINAR

31 January 2023
14:30 – 16:00 CET

For further information, please contact: brussels@activecitizenship.net



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FINAL REMARKS

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While infections and hospitalizations in Europe are currently at a low, the full consequences of the pandemic in terms of NCDs are not yet evident. About it, I well remember the statement of the European Commissioner for Health and Food Safety Stella Kyriakides when last June 2022 she said that “we’re going to be seeing the effects of COVID-19 in the years to come,” adding that many diagnoses and screenings have been delayed, treatments have been postponed, and disease prevention and promotion activities have been put on hold.

And, as shown by our survey, the reduction of the adherence to treatment has been one of the main side effects of the pandemic.

Follow up and possible next steps

From our point of view, one of the main messages of our survey was to highlight the importance of a synergic approach of PAGs & civic organizations in integrating and complementing the institutional and not institutional activities to address primary needs of chronic patients.

And in coherence with this intention, we’ll be committed along 2023 in several training sessions. So, please take note about our next appointment fixed 14 of March (14:30-17:00 CET) and try to join the EU training webinar titled: “Improving health literacy & protecting the value of access to care for better public and patient involvement in mitigating COVID”. In our last [newsletter send out](#)

[yesterday](#) you can find more details and the link for the free registration. As always, they are addressed to representatives of Patients Advocacy Groups (PAGs) & civic associations coming from the EU.

The activity planned in March- realized in the framework of two projects: [“Improving health literacy for better public and patient involvement in mitigating COVID-19 pandemic using interactive and intuitive educational tools”](#) & [“Protecting the value of access to care during - and after - the COVID-19 pandemic across Europe: focus on antivirals](#) it will allow to provide a common set of updated information, share information, identify lessons learned but also to obtain feedback from PAGs.

Conclusion

PAGs have publicly reported, especially during the first wave of the pandemic, an inadequate attention of institutions and the main stakeholders to access and continuity of care for non-Covid-19 patients. The Covid-19 pandemic has certainly influenced the access and availability of healthcare services and medicines' access, especially affecting patients with chronic conditions. The lack of access to care has in fact impacted the adherence to regular check-ups as well as therapies taken for management of those chronic conditions.

The key findings from our survey showed that, during the Covid-19 pandemic, patients' main difficulties concerned the access to specialists' outpatient visit, communicating with their GPs and specialists for urgent matters, and updating their therapeutic plans. The fear to go to the pharmacy due to Covid-19 risk, difficulty of obtaining a prescription, and financial reasons were the reported barriers to medicines access, exacerbating the adherence dimension of the issue. The survey also highlighted the dramatic impact on the psychological status of these patients that developed fear for a further worsening of their clinical conditions without the possibility to access quality healthcare services.

The negative implications of these disruptive events will be tangible in years with a dramatic spike in chronic disease prevalence increase (due mainly to reduced screenings and missed checkups) as well as morbidity-related adverse events. An increase in excess mortality has already been registered and will probably be more evident in the months to come. Our data also highlighted the need of an enhanced collaboration between patient's associations and institutions to develop policies and initiatives.

We are aware of the limitations of the survey both from a methodological and statistical perspective, as well as of the value of the production of civic information. The main objective of this survey is to highlight the importance of a synergic approach of civic organizations in integrating and complementing the institutional activities that in the emergency context failed to address primary needs of chronic patients. Our preliminary analysis represents a first step to collect and analyze real-world data that could support policy making to improve the access and use of essential medicines and ensure the continuity of care in NCDs patients.

One more point we want to stress is the key role that civic organizations have on the empowerment of patients and their families. Through the information services and health literacy initiatives they provide. Empowerment of the patients is critical for adherence to therapies but is, unfortunately, often underestimated. Patients with chronic diseases in particular, not only have to cope with the clinical management of their condition, but also with caring, social, relational, psychological and financial aspects of their disease, factors that often have as much weight as the disease itself on the quality of their lives. The added value of civic organizations consists in a global approach to the patient's health by offering support, information, education, and training, to help them deal with the many difficulties of their daily lives. This global approach is necessary to make patients strong enough to collaborate with their physicians in personalizing the treatment plan, participating actively in the management of their disease, and using healthcare services more effectively. In the current health emergency context what seems to be urgent is the necessity to balance the needs of Covid-19 patients with those of non-Covid-19 patients, starting from the ones suffering from chronic conditions.

Also fundamental is ensuring high attention to the needs of chronic patients with regard to the direct and indirect opportunities linked to the Next Generation EU Fund and the National Recovery and Resilience Plans (NRRPs). In fact, thanks to the NRRPs, each Member State has a great chance to guarantee more resilient healthcare systems in the coming years. At the same time, it is necessary to encourage a larger involvement of all healthcare stakeholders to co-define key priorities. Looking forward to an increase in research funds to be directly allocated in improving adherence, one of the main suggestions is a greater use of tailored digital health solutions to increase therapeutic adherence for the benefit of chronic patients.

Acknowledgements

Finally, as always, I have my list of acknowledgements.

- Once again, thanks to all the panelists, our moderator Alessandro Monaco, our audience and the 38 PAGs involved in our survey. Here the list:

National organizations:

- Together for Life (Albania), Alliance of Transplanted and Operated ATO "Future for All" (Bulgaria), Association of Patients with Cardiovascular Diseases (Bulgaria), Association of Reproductive Health, Pregnancy and Childcare "Smile" (Bulgaria), Innovations Institute (Bulgaria), Пациентски организации Заедно с теб/Patients Organizations "With You" (Bulgaria), CEREBRUM-Association of People with Acquired Brain Injury (Czech Republic), Thalassaemia Society (Cyprus), Σύνδεσμος Καρδιοπαθών Λευκωσίας/ Nicosia Heart Patients' Association (Cyprus), Universal Patient Rights Association (Cyprus), Suomen Kipu ry/Finnish Pain Association (Finland), Aivoliitto ry / Finnish Brain Association (Finland), CHEN-Patient Fertility Association (Israel), Asociacioni Shendetesore Profesional/Professional Health Association (Kosovo), ADICD-Makedonsko Lekarsko Drustvo/Macedonian Medical Association (Macedonia), Malta Health Network (Malta), National Patients' Organisation (Malta), Instytut Praw Pacjenta i Edukacji Zdrowotnej/Institute of Patient' Rights and Health Education (Poland), Polskie Stowarzyszenie Diabetykow/ (Poland), Portuguese League Against rheumatic Diseases (Portugal), St Michael and Sta Maria Diabetic Patient Association Islands (Portugal), APN- Associação Portuguesa de Neuromusculares/Portuguese Neuromuscular Disorders Association (Portugal), Associação de Doentes de Dor Crónica dos Açores/Chronic Pain Patients Association in Azores (Portugal), Força 3P-Associação de Pessoas com Dor/Chronic Patients Association (Portugal), Portugal AVC-União de Sobreviventes, Familiares e Amigos/Stroke Portugal-Survivors, Caregivers and Friends Union (Portugal), ZPN-Association for justice and control (Slovenia), AECOSAR-Asociación Española con la Osteoporosis y la Artrosis/Spanish Association with Osteoporosis and Osteoarthritis (Spain), APDOL- Asociación Española de Pacientes Contra el Dolor (Spain), Fundación Sine Dolore/ Sine Dolore Foundation (Spain), Dutch Association of Dietitians (The Netherlands), EUPREVENT (The Netherlands), Patientenfederatie Nederland/The Netherlands Patient Federation (The Netherlands).

European/International organizations:

- European Coalition for People living with Obesity
 - European Alliance for Patient Access
 - European Kidney Patients Federation (EKPF)
 - International Alliance of Patients Organisations.
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- At the same time, please let me remember that the today's webinar is part of the homonym EU project "Therapeutic adherence during the COVID-19 pandemic across Europe: impact, experiences and perspectives from PAGs & relevant stakeholders" for the second year supported by VIATRIS whom I thank for the trust.
 - At the same time, let me please thank our media partners "Policy and Procurement in HealthCare" and "Health Europe".
 - As always, thank you to the staff of Active Citizenship Network (Bianca first of all, Daniela), our event manager Elisa and to our communication office.

I think we can close our webinar right now, I wish you all a lovely rest of the week. See you soon and stay safe.

Thank you all again and goodbye from Rome. Arrivederci!