

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

COVID-19

SUMMARY OF ACTIONS DEVELOPED BY PLATAFORMA DE ORGANIZACIONES DE PACIENTES

Plataforma de Organizaciones de Pacientes (Spanish Patients' Platform) is an umbrella non-profit organisation comprised of 29 national entities, which in turn bring together more than 1,400 regional and local associations.

With more than 585,000 members, 11,000 staff, and 70,500 volunteers, we work to place the patient at the centre of the health and social systems, to raise their voice and represent their rights.

We have worked and still working on reducing the impact of Coronavirus on people with a disease. In doing so, we have been **actively listening to patients' needs through studies. We developed an epidemiological investigation**, called the "Impact of COVID-19 on patients with chronic diseases in Spain", covering three different areas: health care, labour Impact, and emotional impact. The main results are the following:

HEALTHCARE IMPACT

- Up to 69% of participants stated having planned medical consultations that were cancelled.
- 66.5% of those surveyed found their tests or interventions scheduled postponed until further notice.
- 30.7% of the people stated they encountered different problems and situations in obtaining their medication during the state of alarm.
- 41.4% of the people have had their rehabilitation suspended or postponed.

EMPLOYMENT AND ECONOMIC IMPACT

- 36.4% of the people surveyed had to work in person despite being at risk. Of these, three out of four patients were women.
- The state of alarm has also had an impact on the financial situation of families living with a chronic disease. For 34.1% of the participants, the situation has caused a negative change in their work situation.
- 14.9% of the participants responded that they would soon have to apply for social services.

EMOTIONAL IMPACT

- Respondents were asked about their emotional state before the pandemic and how they felt during the pandemic. The results reflect an increase in negative feelings of 40 percentage points (worry, irritability, nervousness, difficulty sleeping, etc.).
- 40.6% of the sample felt the need for psychological support during the state of alert, although only 3.4% indicated that they received this support service.
- The feeling of loneliness increased 13% of patients from the beginning of the pandemic to the last trimester of 2020.
- Finally, 44% of those surveyed felt pessimism about the future.

Links to full studies:

- [“COVID impact on people with chronic disease in Spain” Phase 1](#) *(available in Spanish only)*
- [“COVID impact on people with chronic disease in Spain” Phase 2](#) *(available in Spanish only)*
- [Patient Care Observatory 2020 Report](#) *(available in Spanish only)*

In the protection of individuals with a chronic illness we work in different areas:

- 1) We strengthened our **free legal clinic service** to provide legal advice to patients and organisations. Most of the consultations received were related to work. At the same time, the legal team keeps us fully informed and advised to defend the rights of patients effectively.

Link to Report:

- [Legal Clinic Service 2020 Report](#) *(available in Spanish only)*.
- 2) We **reviewed occupational safety protocols** developed by the Spanish Ministry of Health to include special safety measures for people at high risk due to previous pathologies.
 - 3) We managed to **offer home delivery of treatments** provided in hospital pharmacies. Thanks to our collaboration with some hospitals, and through volunteer initiatives, we could make such delivery. We still defending the continuity of this service, beyond the pandemic, for those who need it.
 - 4) We strengthened the collaboration and communication among patient organizations, the administration, the scientific community, health professionals and the rest of the health agents to **deliver rigorous information** and combat hoaxes. We continue to strive to offer reliable and accurate information to our partner members and patients. We reinforced communications through our press

office, creating specific actions, content (such as press releases, articles, podcasts), organised online meetings and events to keep all agents involved informed.

As a prelude to the communication campaign for COVID vaccination, and in collaboration with the Ministry of Health and the Spanish Agency of Medicines and Medical Products, we launched the flu vaccination campaign. We developed several video pieces, infographics and other graphic and communication materials.

Links related to vaccination strategy:

- [COVID Strategy of vaccination comparative](#) (*available in Spanish only*)
- [Flu vaccination campaign](#)

- 5) **Vaccination Strategy:** We have defended the inclusion of chronic patients as a priority group in the Spanish COVID vaccination strategy. To do so, we analysed scientific evidence and conducted a study of the vaccination strategies of six European countries. We then held meetings with the Spanish Ministry of Health, regional governments, parliamentary groups, and other stakeholders and presented these data. We finally succeeded in getting chronic patients with more fragile clinical conditions included, and we continue to push for the inclusion of all other patients.

We are currently members of the Communication Committee for the COVID National vaccination strategy, along with other agents and work in advisory from patient perspective on strategies, contents, and communication materials related to COVID vaccination.

- 6) **Enhancing the value of patient organisations:** we developed the awareness campaign “Esenciales” to highlight the “Essential” role played by patients' organisations, especially, in this health crisis. We developed a documentary and video-pills and a digital campaign available on our website.

Link to Campaign:

- “Esenciales” Campaign: <https://www.plataformadepacientes.org/esenciales/>

This document a summary of actions developed by the Platform. More initiatives and information can be found at our website: www.plataformadepacientes.org