



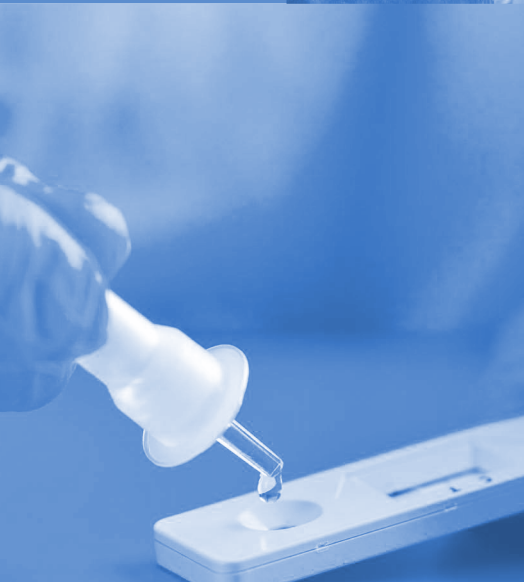
Advisory Board Report

Covid-19 Patient Pathways

23 February 2023

13:30–16:00

On-Line



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List of Participants

ORGANISATIONS

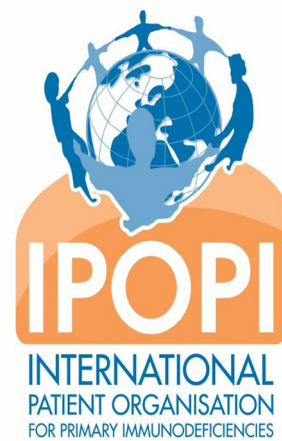
| Name | Country |
|---|-----------|
| International Patient Organisation for Primary Immunodeficiencies (IPOPI) | EU |
| European Society for Immunodeficiencies (ESID) | EU |
| Koalicija udruga u zdravstvu (KUZ) | Croatia |
| Národní asociace patientských organizací (NAPO) | Czechia |
| Cittadinanzattiva (ACN) | Italy |
| Lietuvos pacientų organizacijų atstovų taryb (LPOAT) | Lithuania |
| Instytut Praw Pacjenta i Edukacji Zdrowotnej (IPPEZ) | Poland |
| Federación Nacional de Asociaciones (ALCER) | Spain |
| Plataforma de Organización de Pacientes (POP) | Spain |

MODERATORS/OTHER PARTICIPANTS

| Name | Organisation |
|------------------------|--------------|
| Kit Greenop | RPP Group |
| Kinga Wójtowicz | RPP Group |
| Nayara Maldonado Solis | RPP Group |

OBSERVERS

| Name | Organisation |
|-----------------|--------------|
| Aldona Zygmunt | Pfizer |
| Joffrey Chadrin | Pfizer |



I. Executive Summary

Following the collection of the survey “COVID-19 Patient Care Pathway and existing barriers”, and the analysis of the collected results, on 23 February representatives of nine European and national organisations gathered to further discuss how best to optimise the care pathway for COVID-19 patients. During the meeting, participants proposed concrete measures to tackle a plethora of different challenges posed by the triple epidemic of respiratory syncytial virus (RSV), Covid-19, influenza, which range from the different applicability criteria, the lack of healthcare providers’ knowledge, to the lack of access to testing and treatment.

To kick off the discussions, participants were presented with the results of the survey and shared their perceptions of its outcomes. Each organisation had the opportunity to share reflections on the current state of play regarding placing COVID-19 on the agendas of various stakeholders.

One of the key points of the discussions was the pathway of COVID-19 patients. After having presented an overall structure of the pathway, namely early symptoms, diagnosis, testing, treatment and follow-up, the participants were split into two breakout rooms where they exchanged views on the persisting problems and proposed concrete actions to tackle them.

From the discussions, it became evident that there is a widespread lack of awareness among patients and healthcare professionals (HCPS) on the clear steps to undertake when it comes to following protocol guidelines for ensuring a timely diagnostic, regarding the availability and access to antiviral treatments, and the use of e-health to optimise patients monitoring and follow-up of the disease. Considering prevention and detection measures, participants acknowledged the merits of keeping preventive measures like social distancing, vaccination, and the use of masks, especially for immunocompromised patients and called for the abolition of costs for Covid-19 testing, especially for high-risk groups.

On treatment, it was implied that there is today an insufficient amount of available antiviral treatments across Europe. The patient representatives called for increasing available treatments as well as for the number of available access points. To this end, pharmacists should play a bigger role in providing treatment and the EU shall encourage collective purchases of the latter, so that every European citizen has the same access to it.

The advisory board was the first step towards collecting input on what recommendations should be put forward for both European and national policymakers to optimise the patient’s pathway. For the next steps, policy recommendations that emerged from this meeting will be developed, and after additional feedback is gathered, the recommendations will be launched via a stakeholder event in Q2 of 2023.



II. Presentation of main outcomes

The main outcomes of the survey showed that at a national level, most organisations have not collaborated with national authorities on expanding patient access to Covid-19 treatments - while at the EU level just appears to happen the opposite, meaning there is a need to further expand collaboration at a national level to expand access to Covid-19 treatments.

When it comes to the current awareness level of Covid-19 treatments, results showed that there is sufficient awareness. As such, this does not represent a main bottleneck as the patient community is aware of treatment options. Yet, there is a significant understanding of the fact that there is still a lack of awareness regarding existing guidelines as well as confusion in understanding and applying these guidance.

At a national level, regional inequalities exaggerate disparities in access to Covid-19 antiviral treatment,

as access varies depending on each region's health competency.

When it comes to testing, patients end up being tested in hospitals, analysis laboratories, and primary attention centres, meaning, general practitioners are not contacted as a first step to access testing.

Organisations highlighted that their members have mostly experienced barriers in accessing Covid-19 treatment such as the lack of healthcare knowledge, the different applicable criteria that apply by population or regions, lack of access to testing and resources, and to a lesser extent the healthcare provider ethics and morals. Repercussions of these challenges reflect on longer convalescence periods, eventually hospitalization or deterioration or physical incapacity.

III. Survey Outcomes

During the survey outcomes discussion, participants highlighted that there is a need to avoid known risks such as restriction of access to medicines, treatments, and care for high-risk patients. As to tackle this challenge, participants reinforced the added value that collaboration between all organisations- including patient groups organisations, is essential to fill the existent gaps around Covid-19.

Organisations remarked that regardless of whether Covid-19 is still being placed in their agendas, it does not appear anymore as a priority for governments, meaning, there is an increased low perception of Covid-19 risk and availability of actual data on treatments. Was to be expected, participants claimed that the Covid-19 pandemic has changed

the way healthcare services are delivered, being turned into an economic matter rather than a well-being one.



IV. Patient Care Pathways

Following the survey outcomes and discussion, the Advisory Board progressed with a discussion, which focused on several aspects of Patients Care Pathways, structured in the following stages: symptom awareness, testing diagnosis, treatment and follow-up of Covid-19 patients.

a. Breakout Room one

The discussion started with a note regarding COVID-19 prevention: Mr. Juan Carlos Julian Mauro (ALCER), remarked that vaccination is not always the best way of prevention as people with certain conditions such as transplantation or who are immunocompromised often have lower levels of antibodies.

Regarding detection, participants were unanimous on the need to always provide free testing kits to high-risk groups, as it constitutes the most efficient way of testing the wider population. More specifically, Mr. Robert Hejzák (NAPO), noted that in most cases Covid-19 antigen tests are not provided at no cost anymore, unless they are prescribed by a doctor first, meaning that patients with mild symptoms avoid testing altogether. Ms. Otilia Stanga (IPOPI), referring to the case of Romania, also underlined that high-risk patients are refraining from getting tested due to its costs. Mr. Julián stressed that alongside the self-testing costs, the obstacle Spanish patients face is the lack of equal implementation of active protocols by HCPs, in cases where a patient tested positive.

Moreover, participants also highlighted the primordial role of pharmacists in enhancing testing and called for their greater engagement in providing healthcare services via adopting adequate legislation. The majority of participants also underlined the benefits of digital health technologies such as telemedicine, e-prescription, and e-consultation, which should be further explored. It was judged that enhancing health digitalisation is one of the key aspects of having resilient national healthcare systems.

As regards treatment, participants noted that antiviral treatments are not widely available in most countries. Ms. Vida Augustiniené (LPOAT),

informed the participants that in Lithuania, antiviral treatment is administered only to already hospitalised patients. Reaffirming the lack of available treatment, Ms. Stanga underlined that it is more important to prioritise providing guidance and treatment to high-risk groups, and to expand the mandate of specialists like immunologists, to be able to prescribe the treatment as soon as possible.

Mr. Hejzák, while presenting the situation in the Czech Republic, informed the participants that chronic-disease patients have a shortened care pathway as they can skip contacting first a general practitioner (GP) and can seek advice immediately from specialists – who can adequately prescribe the needed treatment. Moreover, via e-prescription, patients can call their GP and a member of their family can retrieve their medication while at the same time, a self-test is also considered a valid diagnosis and in general, patients know the best pathway in order to get tested and receive treatment. Yet, Mr. Hejzák also noted that regarding the quarantine time, the government modified the guidelines multiple times, which resulted in the general public, minimising the risk of COVID-9 and, adequately, avoiding testing altogether.

Mr. Julián acknowledged the importance of community pharmacies, where patients can retrieve antiviral treatments, without the need to go to the local hospital. However, he noted that there is a widespread lack of awareness of existing treatments, which represents a barrier towards its accessibility.

All participants admitted that there is a general lack of awareness among the general public and also healthcare professionals (HCPs). Mr. Julián alerted that there is a lack of awareness among immunocompromised patients, as many of them are unaware of existing Covid-19 treatments and refer only to vaccines and isolation. He recommended to patients contact their General Practitioner or specialist as soon as they get tested positive to discuss available treatments.

Ms. Stanga admitted that governments have minimised the urgency of the topic and they do not

publish relevant data while Mr. Hejzák noted that overall, the guidelines are very well designed and that the problem lies in that, not every GP is fully aware of these guidelines, especially regarding the treatment of the elderly. Moreover, he highlighted that it is important to investigate if there are other reasons, such as economic ones. Henceforth, the participants called for raising awareness among the ageing population and cardiovascular disease patients, with tailor-made messaging on the necessary precautions for Covid-19 – which is of key importance taking into account its symptoms being similar to other respiratory diseases, such as influenza.

On this point, it was judged that national health ministries play an important role in shaping the policy and educative framework for HCPs. Finally, guidelines should be harmonised to provide a clearer and more solid view among patients and healthcare providers. Nevertheless, according to Mr. Julián differences in patient care pathways exist even for people with the same health condition.

All participants called for the development of concrete follow-up protocols, as well as better data collection on the state-of-play, consequences and treatment of long Covid.

b. Breakout Room two

Regarding prevention measures, the participants agreed that people, especially immunocompromised patients, should continue applying sanitary prevention measures: the use of Covid-19 protective masks and hand hygiene, thus contributing to the wider concept of global health. On this topic, Ms. Paula Echeverría, (POP), admitted that there is a lack of trust in the healthcare system, and in countries like Spain with a more decentralised healthcare system, there is a problem with the collaboration of the primary care chapters. Nevertheless, she stressed that the majority of patients (more than 70%) trust specialist doctors and General Practitioners, followed by pharmacists and nurses and nurses, which are the least trusted figures. Therefore, Ms. Echevarria, along with Mr. Igor Grzesiak (IPPEZ) and Mr. Fabio Candotti (ESID) called for more actions to re-establish the trust between society and healthcare professionals.

Regarding testing and detection, all participants were aligned on the fact that this is not equally accessible for everyone, especially due to its costs, making testing a key barrier towards access to

treatment. People and patients just do not get tested if they have to pay out-of-pocket for it, and hence we shall ensure equal access to testing for everyone. This is primordial for high-risk patients who should get tested once the first symptoms arrive, even if these are not exactly attributed to Covid-19.

Mr. Ivica Belina, (KUZ), also underlined that Covid-19 testing sites are not equally distributed within the countries and thus there are geographical inequalities in access to testing. Therefore, participants reaffirmed that health authorities should promote self-testing and allow local diagnosis labs to take a bigger role in the national healthcare system, so that they also provide data to national authorities. Additionally, as a lesson learned from the pandemic, Member States shall upgrade the role of pharmacists by better integrating them to support the healthcare system, regarding testing as well as vaccination.

On treatment, all speakers noted that there are inequalities in the availability and access to treatment. Mr. Mariano Votta (ACN), underlined that antivirals are provided within the pharmacies of the hospitals and that there is a long bureaucratic procedure for patients to access antiviral treatments, thus risking further deterioration of their health. Mr. Belina also complemented that in Croatia, antiviral treatments are scarce within the country, and hence called patient organisations to put pressure on the governments to provide additional prophylactic medication as well as additional testing to patients. The reason for this is that it is not financially feasible for smaller countries, where hospitals have a limited supply of antiviral treatments and testing capacities, to provide both at a large scale as this would threaten their financial stability. Participants also called for the shortening of the bureaucratic procedure from a positive Covid-19 test to receiving antiviral treatment.

Nevertheless, raising awareness on Covid-19 prophylaxis, available treatments, and best pathways was signalled as the priority according to all participants in the discussion. Mr. Igor Grzesiak, acknowledged that in Poland there is a significant distrust towards HCPs, with only 60% of the general population putting trust in them, and thus, more focus must be put on education. Therefore, after the establishment of a clear and understandable patient pathway, communicating it to the wider public should be the priority. Mr. Grzesiak shared

with the participants a relevant report that IPPEZ published on Diagnosis and Treatment Pathway for Covid-19 patient in Poland. According to the report, not all patient groups have the same information on the availability of antiviral treatments and thus many patients do not pursue such treatments. Therefore, he underlined the importance of communication and education of all actors of the healthcare systems and their engagement with the wider public, as there is an important lack of information.

Mr. Votta and Mr. Candotti both confirmed the importance of communication, especially in relation to high-risk groups, which should be done via general practitioners to alert those patients early on. Participants also acknowledged the significance of maintaining an open dialogue with HCPs, to keep them up to date on novel treatments and noted that the long bureaucratic procedures halter the dialogue between patient groups, scientists, pharmacists and healthcare professionals during the pandemic. To this end, participants called for the identification of high-risk patients and provide them with treatment in a timely manner when it is most needed, for supporting patient organisations in raising awareness - who can communicate reliable information to their members. The important role in awareness raising was also attributed to nurses. Finally, Mr. Belina also noted that relevant information must be circulated via traditional media outlets rather than only via the internet. Furthermore, Mr. Votta called the EU to launch a public procurement for antiviral treatment similar to the one for Covid-19 vaccines, to ensure its

availability to all member states, and support the national healthcare systems via the Resilience and Recovery Fund of the EU, and on the other hand, the healthcare professionals, who have also been severely affected by the pandemic.

Regarding preparedness, Mr. Candotti also urged the EU to financially support research centers on testing new vaccines and drugs that the EU is more prepared for the next pandemic. All participants aligned on the merits of telemedicine and e-prescription as a complement to traditional healthcare, but, as Ms. Echeverría underlined, what is of utmost importance is to integrate patients into the decision-making processes so that they become the center of attention for policymakers and healthcare professionals alike.

Concluding the session, Ms. Echeverría highlighted that the healthcare system should become more flexible and adaptable, more digital and coordinated. Moreover, patients should be given a more prominent role in decision-making, while enhancing their engagement in patient organisations.



V. Next Steps & Closing Remarks

Based on the fruitful discussions held by the Advisory Board, the main recommendations will be gathered. Once created, the participants will be given the opportunity to share their further input. Policy recommendations will be published through a stakeholder event.

The event is sought to take place in early May, and it will be in person in Brussels.

The Advisory Board meeting was organised with the financial support of Pfizer.
The meeting was non-promotional, and no specific medicines were discussed.