



Joining forces for action

RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates 2022

Rare cancer during COVID-19

Industry perspective

Federica Castiglione

Executive Director Patient Engagement, Europe Novartis

23rd Code of Ethics Commitment on Patient Engagement underscores visibility to the importance of patients to our strategy

Our Commitment

To consistently and systematically engage patients along the medicine's lifecycle. Together with patients we can reimagine medicine by developing innovative medicines faster and creating broader access.

Why it matters

Patients deserve to live their best lives possible. Co-creation with the community is necessary to optimize the benefit of medicines for patients and society.



Novartis response to the COVID-19 pandemic is guided by the Novartis Commitment to Patients and Caregivers

The safety and wellbeing of patients is our primary concern as we respond to the COVID-19 pandemic. Novartis is working to ensure supply of our medicines, enhance virtual services, protect the integrity of clinical trials and support patient organizations. Our response is guided by the Novartis Commitment to Patients and Caregivers.

The Novartis Commitment to Patients and Caregivers

Only by working together and delivering on the four pillars of our Commitment, can we improve outcomes for patients and change the practice of medicine

40+

PATIENT ORGANIZATIONS representing

200m

PATIENTS contributed to its development

110 000

NOVARTIS ASSOCIATES' own it as an aspiration to embed the perspective of patients and caregivers systematically in our decision-making

Our Commitment is based on four pillars



Respecting and understanding the patient community perspective



Conducting responsible clinical trials



Expanding access to our medicines



Recognizing the importance of transparency and reporting

Patients (and Patient Organizations) in COVID-19 times encountered issues of different nature

- *Health risks*
- *Difficulties in access to healthcare*
- *Difficulties in access to treatments*
- *Delays in treatment visit and plans*
- *Challenges related to recruiting, enrolling and treating patients in clinical trials*
- *Loneliness and isolation*
- *Need to adapt to new digital ways of communicating*
- *Patient Organizations: diversion of funds to COVID-19 initiatives*
- *Patient Organizations: delays, reconversion of resources and activities, digitalization*



As the coronavirus (COVID-19) continues to spread around the world, Novartis is closely monitoring the evolving situation with one major concern: **the health and safety of our employees and patients.**



We are aware that this unprecedented public health crisis **has an even greater resonance for people suffering from various pathologies** who, in addition to the concern related to the pandemic, have specific issues related to their disease and the follow-up of their treatment.

We reaffirm all the commitments we have made to patients, patient associations and healthcare professionals.

Novartis addressed patient issues generated by COVID-19 in different ways

COVID - 19 Novartis Response

In the face of a global crisis, Novartis has quickly mobilized R&D capabilities, medicines, clinical trials expertise and philanthropic aid to address the coronavirus pandemic.



MLR ID 187079 Novartis Pharma AG, CH 4002 Basel Switzerland 2/2022



- To support patients experiencing delays in clinical trials, protocol deviations reviews were prioritized, drug delivery at home was implemented where allowed (local experiences), patient support programs were potentiated
- For patients who are participating in Novartis clinical trials we have enacted mitigation plans where needed to protect the integrity of our trials and help ensure continuity of treatment.



- Support: access a greater pool of funding
- We eliminated the need to repeat the time-consuming reputation check for Patient Organizations **if that was recently done**
- We developed a rapid-response and approval process in collaboration with the legal/compliance team to ensure reviews and approvals of funding proposals were **completed within 24 hours**
- We worked with the finance team to ensure that approved funding requests were paid out in a **maximum of 30 days**
- We **expanded the range** of funded activities including COVID-19 related ones
- In collaboration with the legal/compliance team we gave the possibility to **re allocate funded activities to COVID-19 ones**
- Help was given to Patient Organizations in the **diffusion of their COVID-19 initiatives** and databases/toolkits, fighting fake information



- The COVID19 pandemic has accelerated our digital transformation, including in the ways we engage and interact with our stakeholders, bring our products to market, and meet the needs of patients. These initiatives include the **development and implementation of personalized engagement models enabled by digital technologies**, the demand for which has increased in response to the COVID-19 pandemic.
- The change to **fully virtual Patient events** (e.g. Advisory Boards, GOPIPs – Global Oncology Patient Insight Panels, etc) was fast and effective
- **EPIS2020** (European Patient Innovation Summit) was organized around the new digital opportunities arising from COVID-19 for patients and issued recommendations



The above sketchnote was captured during the EPIS 2020 Summit that took place on the 5th November 2020. The sketchnote illustrates the discussions of patient community representatives on 'Making the most out of new opportunities for engagement arising from COVID-19'. Please visit <https://www.episummit.net/> for further information and resources.

Organised and funded by
NOVARTIS | Reimagining Medicine

EPIS is co-created with the EPIS Steering Committee FUSE ID: 6703 November 2020

Ensuring access and supply of medicines

EFPIA: Policy proposals to minimize medicine supply shortages in Europe Lessons from COVID-19 crisis

- Ensure a consistent and workable definition of medicine shortages
- Ensure a better understanding of the root causes and drivers of shortages.
- Improve understanding and transparency of patient needs at member state level for appropriate planning forecasting.
- Address national stockpiling requirements
- Facilitate the production and supply of treatments impacted by the pandemic through regulatory flexibility to meet patients needs
- Reach a careful balance between free movement of goods and the need to efficiently supply medicines based on patient needs as well as re-balance stocks across borders.
- Ensure that procurement policies do not nullify the intended effects of supply side policies
- Ensure the availability of critical medicines at EU level in line with Member States' patient needs
- Ensure continuous dialogue between competent EU and national competent authorities, and manufacturers with a view to addressing any imbalances between demand and supply

Source: [Phttps://www.efpia.eu/media/554682/covid-19-drug-shortages-efpia-position-paper.pdf](https://www.efpia.eu/media/554682/covid-19-drug-shortages-efpia-position-paper.pdf)aper 150520

Some Countries Experiences in Patient Engagement

Novartis Germany

- Hybrid model for clinical trials
- Virtual AdBoards on Patient needs in times of COVID-19
- Donation of 100.000 respirators to the Federal Ministry of Health

Novartis Greece

- free home delivery of treatments to approximately 6,500 patients, who are unable to supply private pharmacies, are not served by a corresponding program of the health system and belong to a high-risk group

Novartis Portugal

- Patient Support Programs remained active through virtual care (telemedicine, online nurse support)

Conclusions

- COVID-19 generated problems and hurdles to the Patient Communities to which Novartis responded guided by the Novartis Commitment to Patients and Caregivers
- Novartis response was relentless in 4 big pillars:
 - Enhancing virtual services
 - Ensuring Access and Supply of Medicines
 - Protecting Integrity of Clinical Trials
 - Supporting Patient Organizations
- According to local laws and regulations, Country and Regional Novartis Patient Engagement Teams provided local support and put in place patient focused actions
- We are committed to treasure the experiences and learnings we achieved during the pandemic times to improve even more our future actions in favour of the Patient Community in the (hopefully) post-COVID19 world

R
CANCERS
EUROPE
E

Joining forces for action

Thank you!