

# Special Report: COVID-19 and the Patient Perspective

A summary of a global panel discussion



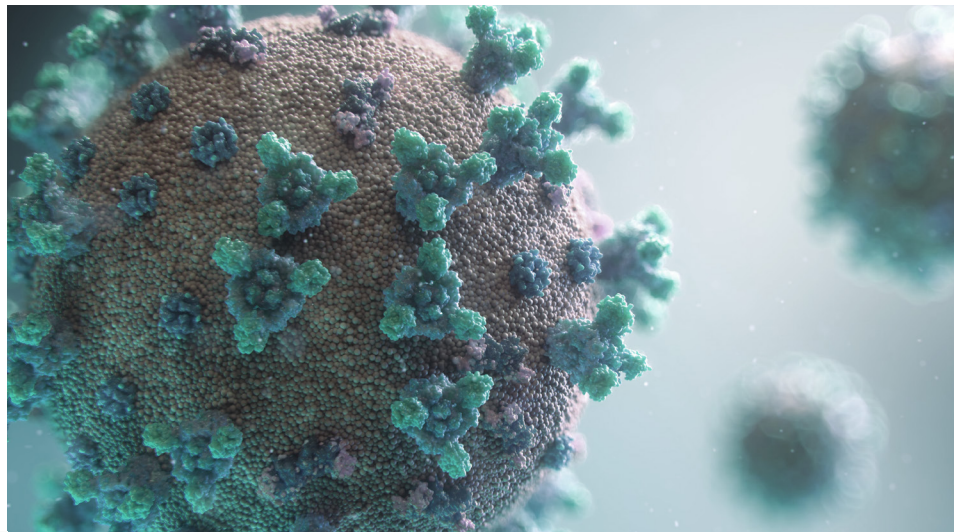


# Special Report: COVID-19 and the Patient Perspective

## A summary of a global panel discussion

The ongoing COVID-19 (SARS-CoV-2) pandemic has created unprecedented challenges, affecting people in every area of our world. Health systems and health care have been significantly impacted. In fact, according to a World Health Organization (WHO) pulse survey, from January through March 2021, 94% of participating countries reported some kind of disruption to health services. Among the most heavily impacted were primary care, rehabilitative, palliative and long-term care services.

In August 2021, Merck brought together patient advocacy leaders from around the world to discuss their assessments on the trends and shifts in health care and the impact on patients during the next phase of the pandemic.



The following report summarizes our panelists' insights, lessons learned and projections of what lies ahead for health care from the patient perspective. Among the global trends highlighted by our experts were:

- Defining and characterizing the “new normal”
- Understanding the future of patient care
- The challenges of COVID-19: focus on mental health
- Addressing health care disparities and health equity
- Embracing patients and patient advocates as part of the solution
- Partnering for success

### Our experts included:



**Dr. Michelle Vichnin**  
executive director,  
Global Patient Advocacy  
**Merck & Co., Inc.**  
(host and moderator)  
*United States*



**Dr. Sawsan Al Madhi**  
director general  
**Friends of Cancer Patients**  
*United Arab Emirates*



**Dr. Ratna Devi**  
board chair  
**International Alliance of  
Patients' Organizations**  
*India*



**Luciana Holtz**  
founder, president  
**Instituto Oncoguia**  
*Brazil*



**Elisabeth Kasilingam**  
acting executive director  
**European Patients' Forum**  
*Belgium*



**Randall Rutta**  
CEO  
**National Health Council**  
*United States*

# Defining and characterizing the "new normal"

The panelists discussed their thoughts about this so-called "new normal," as for many people, these times feel like anything but normal.

## Everyone is learning something new

**Dr. Devi** of the International Alliance of Patients' Organizations noted, "It feels like this pandemic is going to stay forever and you have to learn to live with it. We're in a phase where everyone is learning something new – whether it's making new drugs, new vaccines, new methods of service delivery, new methods of access to health care, new methods of financing, with digital coming in a big way."

## Resilience and a holistic approach to care

**Mr. Rutta** of the National Health Council noted that "any new normal is still emerging and the pandemic requires us to be resilient and agile in responding to realities that are changing every day. It's a beginning for fresh thinking and new ways to advance personal and patient community health and wellbeing."

**Dr. Al Madhi** of Friends of Cancer Patients agreed, noting that "COVID-19 has changed everything. We now need to empower a more holistic approach to health care. Health is the combination of being physically, mentally, psychologically and spiritually well."

## Uncertain times

"Pre-COVID-19, the health care systems were already disrupted and inequalities were present. The pandemic has enhanced the gaps and flaws of our systems," said **Ms. Kasilingam** of the European Patients' Forum. "And so, this situation, the 'new normal' as we call it, is probably a temporary state of uncertainties."

**Ms. Holtz** of Instituto Oncoguia agreed, noting, "It's not easy to admit that we have to face a new normal. We will need to take the opportunity to put into practice the lessons learned from this very difficult phase."

## Our new relationship with technology

People's relationship with technology will likely deepen in the wake of COVID-19 and other crises, a recent survey found. This is because more segments of the population are relying on digital connections for work, education, health care, daily commercial transactions and essential social interactions. Some describe this as a "tele-everything" world.<sup>1</sup>



# Understanding the future of patient care

As a result of the pandemic, health care systems have been forced to quickly adapt. The panelists explored what trends they are observing with patient care.

## Acceleration of innovation

“COVID-19 caused a dramatic disruption in care systems for people with chronic conditions and disabilities that propelled telemedicine and online capabilities forward, including an array of digital devices and systems for monitoring, diagnosing and promoting health,” noted **Mr. Rutta**. He added that these innovation advances are, “more important than ever.” The pandemic exposed inadequacies of health care systems and models that are outdated “relative to 21st century medicine and innovation.”

## Adoption of telemedicine/telehealth

**Ms. Holtz** said that the increased use of telemedicine/telehealth was one of the few good results of the pandemic. She explained that her country is very diverse and includes areas without physical access to health care professionals. “Keeping telemedicine available will be necessary.” However, she noted that “we must also remember the importance of access to the Internet so that we can address the so-called digital divide.”

## Human approach is still needed

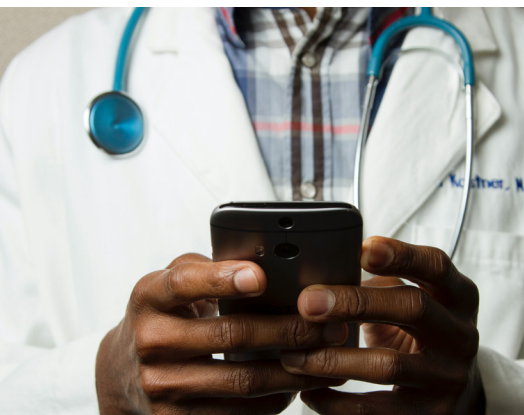
**Ms. Kasilingam** elaborated, “We received comments from patients saying that, despite the digital/remote access and the availability of the services, they’re missing the human connection with the health care professionals. This moment is important as it provides the opportunity to explain and share their needs and concerns with the healthcare professionals.” Moreover, it’s important to be aware that “there’s a distinction to be made between patients who are comfortable with the digital services and others who are not.”

## A rise in telehealth

Physicians and other health professionals are now seeing 50 to 175 times the number of patients via telehealth than they did before the pandemic.<sup>2</sup>

## Increase in smartphone use

The Mobile Economy 2020 report predicted that smartphone connections in sub-Saharan Africa will nearly double by 2025.<sup>3</sup>



# Understanding the future of patient care

## Data privacy is a concern

**Dr. Vichnin** noted the importance of data privacy, which has been heightened by the increased use of technology during the pandemic, stating, “People want to ensure their data are secure. They would like their data to be portable so that they can access their information from anywhere, and they expect precision in the way the data are used, especially for personalized care.”

**Dr. Devi** agreed, noting that data portability across systems and platforms is a big issue. “When information is not shared, it makes it very difficult for patients to manage.”

## Mobile delivery of care

**Dr. Al Madhi** noted that mobile health care delivery or a “mobile approach” has become more important during COVID-19. An example is a specially equipped van where patients can get screened for breast cancer. While mobile approaches were used before the pandemic, they are now being used in other ways, including mobile medical clinics to vaccinate children.

## Addressing delays in diagnosis

**Ms. Kasilingam** emphasized, “Many delays with seeking care and diagnosis of diseases have impacted chronic patient communities. In the longrun, this will lead to negative outcomes for patients and increase the costs of diseases on society.”

**Ms. Holtz** shared her concerns as well, stating, “In the world of cancer, there are serious tests, diagnostics and treatments.” If people do not get the needed care, she said, “maybe we will face an epidemic of advanced cancer cases.”

### Data protection in the EU

More than 90% of Europeans say they want the same data protection rights across the European Union (EU) regardless of where their data is processed.<sup>4</sup>

### Mobile increases access

Mobile clinics offer flexible and successful options for treating isolated groups as well as newly displaced populations. When coordinating a crisis response, WHO arranges for mobile health care teams to go by foot, bike, moto, boat or vehicle.<sup>5</sup>

### A drop in cancer screenings

Sharp declines in cancer screenings have been observed globally during COVID-19.<sup>6</sup> In the U.S. alone, there was an estimated cancer screening deficit of 9.4 million in 2020.<sup>7</sup>





# Understanding the future of patient care

## “Build back with more resilience”

This concept refers to the need to build health systems and interventions to be more resilient and better than they were before the pandemic. **Dr. Devi** explained, “We need to have a system that doesn’t collapse when there is some kind of emergency, whether it’s a pandemic or an earthquake or some other disaster. Building back with greater resilience is to have a care continuum pathway that includes prevention, so it takes care of you when you’re healthy, and does not only focus on sickness and acute care when you’re sick.”

## Impact on research agenda/pandemic preparedness

**Dr. Al Madhi** noted, “In my view, this decade is going to be the decade of infectious disease, unfortunately.”

**Dr. Devi** agreed, “This is not a one-time pandemic. We could have future pandemics; we could have future superbugs. We know that antimicrobial resistance is a very real threat. We – as the patient community, as leaders in global research, as governments, as policy makers – are actually looking at this future and preparing for it. We need investment. It’s one thing to understand what the problem is, but a whole new aspect to come to solutions. And for that, all people who are involved in research or who are interested in improving health care outcomes have to come together and discuss what kind of strengths and skills they can bring to the table.”

“Yes,” agreed **Ms. Kasilingam**. “We need to prepare our society for the upcoming crisis, whatever form it will take. We have to make sure that our systems are better prepared, that we use these learnings from the past 18 months and use the opportunities to build on those.”

**Dr. Devi** also noted that research to study the long-term effects of COVID-19 (post-COVID conditions or so-called “long COVID”) will be important, as the pandemic has exposed the deep interrelationship of existing morbidities that aggravate adverse outcomes in patients with COVID-19.

## Pandemic and Epidemic Intelligence

WHO and the Federal Republic of Germany recently announced the creation of the WHO Hub for Pandemic and Epidemic Intelligence. Based in Berlin, the Hub will “lead innovations in data analytics across the largest network of global data to predict, prevent, detect, prepare for, and respond to pandemic and epidemic risks worldwide.”<sup>8</sup>

# The challenges of COVID-19: focus on mental health

In addition to the enormous loss of life and impact on physical health, COVID-19 has taken a toll on people's mental health. We are "COVID-fatigued." The pandemic has especially affected certain groups, including health care and other frontline workers, students, people living alone and those with pre-existing mental health conditions. And services for mental, neurological and substance use disorders have been significantly disrupted.

"Mental health is going to be our next pandemic," said **Dr. Al Madhi**. "It's going to be a big catastrophe, on a colossal level." She acknowledged that people are tired of hearing about COVID-19. "Everybody's looking forward to the day where they sleep and wake up and they can go about their lives as usual, whatever they used to do before COVID-19."

Since so many people will need mental health services, "there are concerns about the availability of enough mental health professionals to support the patients," noted **Ms. Kasilingam**.

**Ms. Holtz** emphasized that people have been expressing feelings of fear and anxiety. "We saw very scared patients, almost paralyzed; people are suffering." Her organization developed online communities for cancer patients to support each other.

**Dr. Devi** expressed concern about the mental health of children and populations with special needs and aged populations, many of whom have been isolated for long periods of time from people outside their own household.

## Concerns about mental wellbeing

A recent survey in Asia Pacific revealed that more than one-third of people reported feeling concerned about their health as a result of COVID-19. Managing mental wellbeing was at the top of the list.<sup>9</sup>

## Improving mental health care

WHO launched the "WHO Special Initiative for Mental Health (2019-2023): Universal Health Coverage for Mental Health" to ensure access to quality and affordable care for mental health conditions in 12 priority countries to 100 million more people.<sup>10</sup>

This program is in response to a high incidence of mental health issues across the globe. For example:

- Depression is one of the leading causes of disability
- Suicide is the second leading cause of death among 15-29-year-olds
- People with severe mental health conditions die prematurely – as much as two decades early – due to preventable physical conditions



# Addressing health care disparities and health equity

The pandemic has certainly highlighted gaps in current health care systems and care models. It is forcing us, as a society, to grapple with health care disparities and aim for greater health equity.

**Dr. Al Madhi** called COVID-19 “the equalizer” and emphasized, “It didn't matter if you had a fancy ICU or if you were in a rural area, people were dying. It didn't matter if a person was rich or poor; as COVID-19 progressed, disparity became even more obvious.”

The panelists discussed ways to address those inequities. Highlights include:

## Seize this moment

“It’s a call to action and shame on us if we don’t take advantage in responding to the pandemic to close those gaps,” **Mr. Rutta** emphasized. He added, “I think we need to sharpen our focus on equity and inclusion. It’s a matter of social justice, it’s a moral imperative, and we just can’t lose this momentum. All of us have a vested interest to make sure that as we move health care forward, as we move past the pandemic, no part of our community, no group of patients is left behind.”

## Social determinants of health

Medical care is estimated to account for only 10-20% of the modifiable contributors to health outcomes for a population. The other 80-90% are broadly called the social determinants of health (SDOH), which are health-related behaviors, socioeconomic factors and environmental factors.<sup>11</sup>

## Addressing social determinants of health (SDOH)

**Ms. Kasilingam** stated, “To address inequities, we must handle the needs of all patients and must examine SDOH. We need to look at the health and social care systems together. All aspects of a person’s life are as important as the treatment they receive from health care professionals – and ultimately impact the clinical outcome.”

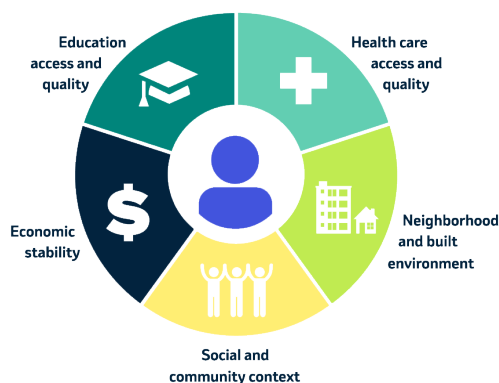
## Building health literacy

Creating health information that people can understand is essential so they can make informed decisions about their health care. **Ms. Holtz** noted, “Educating the citizens about health science and health literacy helps us to fight the misinformation which is so prevalent.” Digital literacy is also important, noted **Dr. Devi**. “There has been a proliferation of apps and other digital tools, and not every patient can use them. They need to be educated on how to use this technology.”

## European health literacy levels

In Europe, nearly half of adults reported having problems with health literacy and not having the necessary knowledge to take care of their health and that of others.<sup>12</sup>

## Social determinants of health



Source: Healthy People 2030



# Embracing patients and patient advocates as part of the solution

The panelists noted that, because of what we have learned through the pandemic, there are opportunities for a renewed focus on health and prevention.

**Dr. Al Madhi** explained, “There is now a really good appetite in the population to start speaking about health and wellness. We need to be compassionate at this stage and come together collectively.”

According to **Mr. Rutta**, “We’ve got to do everything we can as advocates for patients to really make sure that – first and foremost – they’re involved in every aspect of decision-making.” He added that patients should be engaged in clinical trials and medical innovation efforts so their needs and perspectives are understood. “It’s particularly important to include patients with diverse backgrounds and those with multiple conditions. Putting patients at the center of how decisions are made is a winning strategy for all of us.”

**Dr. Al Madhi** agreed, noting, “We should look at how other industries involve their end user because that’s what the patient is, the end user of the system.”

**Dr. Devi** added, “You should take the patients’ voices into consideration and ask what is important to them before you start designing or ramping up an existing technology.”

The COVID-19 pandemic has also shown the added value of patient organizations.

**Ms. Kasilingam** said, “We have seen a lot of patient organizations step up. They connected with patients who needed basic support and information because they were lost and overwhelmed.” Patient organizations also represent the “voice of chronic patients” and help policy decision-makers to “prioritize in the right way so that patients with chronic diseases are not adversely affected.”



# Partnering for success

During the roundtable discussion, panelists discussed the importance of partnering for success. There was universal agreement that collaboration across all sectors will be critical for addressing the enormous challenges that lie ahead, and that investment in health care should be prioritized.

## Importance of partnerships

“Let’s take advantage of what we saw and learned in the pandemic, and I really believe that we will only succeed if it is in partnership,” said **Ms. Holtz**. “We saw several examples of public-private partnerships that helped a lot in different situations here in Brazil, from the purchase of masks to delivery of vaccines.”

**Ms. Kasilingam** agreed, adding, “It means that we have to work together, and I really believe in a collaborative approach to make sure that we reach our goals. In fact, something that was amazing during the pandemic was that we saw several consortia and collaboration networks that came together and acted quickly to improve services and care. Working in silos will not deliver the right outcome.”

“Partnerships are at the core of success for patient organizations like mine,” noted **Dr. Devi**. “They help us to learn fast, disseminate and amplify the learnings, and together explore solutions to new challenges.”

**Mr. Rutta** concluded, “We need to look at the ways we finance health care, from basic health care to the really almost science fiction-type innovations that are occurring through medical discovery. We need to have a way to finance this innovation and support it at a personal level and at a systems level to make sure that we can truly advance the science to help the patient.”

**“If you want to go fast, go alone. If you want to go far, go together.”**

**— African proverb**

## Financing the future

### References (all accessed on September 29, 2021):

<sup>1</sup> <https://www.pewresearch.org/internet/2021/02/18/experts-say-the-new-normal-in-2025-will-be-far-more-tech-driven-presenting-more-big-challenges>

<sup>2</sup> <https://www.ama-assn.org/practice-management/digital/after-covid-19-250-billion-care-could-shift-telehealth>

<sup>3</sup> <https://www.thelancet.com/action/showPdf?pii=S2589-7500%2820%2930252-1>

<sup>4</sup> [https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu\\_en](https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu_en)

<sup>5</sup> <https://www.who.int/emergencies/partners/mobile-clinics>

<sup>6</sup> <https://ascopubs.org/doi/full/10.1200/JGO.21.00033>

<sup>7</sup> <https://jamanetwork.com/journals/jamaoncology/fullarticle/2778916>

<sup>8</sup> <https://www.who.int/news/item/05-05-2021-who-germany-launch-new-global-hub-for-pandemic-and-epidemic-intelligence>

<sup>9</sup> <https://www.swissre.com/dam/jcr:f95fd82b-fb98-44d2-8cf0-981682963915/swissre-institute-expertise-publication-asia-covid-19-consumer-survey-2021-factsheet.pdf>

<sup>10</sup> [https://www.who.int/health-topics/mental-health#tab=tab\\_1](https://www.who.int/health-topics/mental-health#tab=tab_1)

<sup>11</sup> <https://nam.edu/social-determinants-of-health-101-for-health-care-five-plus-five>

<sup>12</sup> <https://academic.oup.com/eurpub/article/25/6/1053/2467145> <http://pubmed.ncbi.nlm.nih.gov/25843827>

Thank you to our esteemed panelists for their insights and perspectives on patient engagement and care in this next era of COVID-19.

On our mission to save and improve lives, Merck puts patients at the center of everything we do. Learn more about our commitment to patients at: [www.merck.com/patients](http://www.merck.com/patients)



*As part of our commitment to patients, this document underwent a health literacy review to ensure clarity of communication.*