

EPIS explores how COVID-19 is shaping the future of digital engagement within healthcare " >

Patient community representatives call for improved digital health literacy, standardised digital platforms, and co-creation of digital solutions.

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The COVID-19 pandemic created a number of different challenges for the patient community. Through those challenges, however, came opportunities to utilise digital engagement, and an accelerated use of digital tools. Participants of the European Patient Innovation Summit (EPIS) explored the positive and negative aspects of digital engagement during the COVID-19 pandemic at EPIS 2020 and made recommendations on how patients can continue to benefit from digital engagement in future.

The positive impact of these digital tools has been that they help patients get the right information from specialists without creating confusion.

Europa Donna Albania, Albania

Patient community representatives at EPIS noted that digital solutions allowed them to maintain continuity of care during the COVID-19 pandemic, with virtual communications and social media providing new options for them to communicate with healthcare services. Through digital engagement, patient organisations were able to stay connected with their members, whilst patients themselves were able to interact with healthcare professionals (HCPs), family members and friends.

The biggest challenge has been having to over-rely on online platforms which can cause fatigue. The lack of human interaction has also been difficult for some people living alone

Migraine Association of Ireland (MAI), Ireland

Despite many patients turning to digital solutions throughout 2020, EPIS participants expressed that a lack of face-to-face interaction with HCPs caused many to feel isolated and unable to access certain services. There were also many patients who did not understand how to use technological solutions properly, as well as some resistance from HCPs to the use of digital tools.

Key Recommendations

At EPIS 2020, participants voted on a series of recommendations that were developed in small discussion groups led by patient community members. These recommendations contained suggested actions that key stakeholders can take to ensure that patients continue to benefit from digital engagement opportunities. In general, they identified the need for greater education to improve digital health literacy, so that digital solutions can be effectively utilised moving forward. Also highlighted was the need for standardisation of digital health platforms for HCPs and patients, and to ensure digital health solutions are being co-created with patients and HCPs.

- **Patient Organisations** – Participants called for the creation of a national, digital patient platform that can be utilised in online consultations with HCPs, as well as for training and education. They noted that patients must be educated around digital health solutions, and that any digital innovations must be centered around improving quality of life for patients – rather than benefitting technology companies or

large healthcare organisations.

- **Healthcare Professionals** – There was a call for the implementation of standardised digital platforms that can be used by both HCPs and patients. Education was also raised as an important factor – it was suggested that HCPs need access and training to make the most of new digital opportunities.
- **Policy Makers** – Providing a central educational tool that can be distributed to patients and HCPs was identified as a key recommendation for policy makers. Also highlighted was the need for national, centralised telemedicine systems for virtual clinics, as well as making it easier for patients to interact directly with HCPs or health services.
- **Technology Developers** – The importance of co-creating digital solutions, ensuring patients and HCPs are involved early on in the development process, was highlighted as a key recommendation. It was also noted that new tools must respond to a specific unmet need that is relevant to patients – and that clear objectives must be established at the start of development.

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Resources resulting from EPIS 2020 have been made available at the EPIS website. These tools will help support EPIS participants with the local implementation of these recommendations on digital engagement.

COVID-19 may have accelerated digital engagement, but there is still so much we can do to ensure patients get the most from it. We need improved digital health literacy, seamless patient access to their own data, standardisation in digital health technologies for both patients and healthcare professionals, and digital solutions that are co-created from inception. Only then can we truly address the healthcare needs to the patient community.

Gilliosa Spurrier-Bernard, EPIS Steering Committee member, France

About the European Patient Innovation Summit

Established in 2016, the European Patient Innovation Summit (EPIS) is a platform for patient advocates from across Europe to discuss all aspects of digital health and to achieve consensus on the patients' position on different issues relating to the digital world and health. EPIS includes an annual event and is organised and funded by Novartis. Content is developed together with a Steering Committee of representatives from patient organisations who advocate on behalf of the patient community.

In 2020 and early 2021, more than 250 patient advocates, across 40 countries and from different disease areas, came together in a virtual meeting series alongside the EPIS Steering Committee.

Additional Resources

[EPIS Digital Engagement Toolkit](#)

[EPIS 2020 mini-interview series \(PDF 2.3 MB\)](#)

[EPIS 2020 infographics \(PDF 1.0 MB\)](#)

[EPIS 2020 sketch notes \(PDF 9.3 MB\)](#)

European Patient Innovation Summit publishes call for action to ensure greater patient involvement in digital health solution development

EPIS participants call for all stakeholders to ensure the patient voice is at the heart of the development of digital health solutions

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