

Patients in a digital world: digital engagement during the COVID-19 pandemic

There is no doubt that the COVID-19 pandemic has changed patients' lives and created challenges that could never have been anticipated. Patient representatives were asked about their **experience** with **digital engagement during COVID-19** and asked to vote on the most **positive** and **negative** aspects of this.



Positive experiences of digital engagement included an increase in virtual communications, rapid creation of new resources and a dramatic increase in social media use.¹



“

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

”

The most positive aspects of digital engagement²



29% Maintaining continuity of care

28% Having virtual access to advice and support from health professionals digitally

15% Staying informed

11% Being in control and empowered

9% Connecting with family, friends and peers

8% Minimising the risk of a potential COVID-19 infection

Positive experiences of patient advocates with digital engagement during COVID-19³





Negative experiences of digital engagement included struggling with loneliness, lack of access or understanding on how to use digital tools and missed human interaction.¹



The most negative aspects of digital engagement⁴



- 35%** Having less face to face interactions and/or time with health professionals
- 18%** Health professionals resisting the use of digital tools
- 16%** Unable to use technology properly
- 12%** Lack/limited access to the infrastructure (e.g. internet, smart devices etc)
- 12%** Inability to access certain services/support digitally
- 7%** Issues with data sharing, interoperability and privacy

Negative experiences of patient advocates with digital engagement during COVID-19⁵



“ *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

Where to next for digital engagement?

At the EPIS 2020 Summit, **84%** of participants agreed and/or strongly agreed that **the benefits of digital engagement for patients far outweigh the disadvantages.**



Furthermore, 7.98 was the average rating given by patient advocates on their experience of using digital technologies during COVID-19.

1 – Not at all positive / 10 – Extremely positive

Footnotes

1. EPIS (2020), Patients in a digital world: Three questions on digital engagement and solutions during the COVID-19 pandemic <<https://www.episummit.net/resources.html>> **2.** These results are based on the polling from 130 patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020. **3.** This word cloud was created via the 88 word entries received from patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020. **4.** These results are based on the polling from 139 patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020. **5.** This word cloud was created via the 94 word entries received from patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020.

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How can we ensure that patients continue to benefit from digital engagement opportunities?

At the **European Patient Innovation Summit 2020 (EPIS 2020)** that took place on the 5th November, patient leaders and advocates from across Europe connected to discuss **digital engagement** – how, within healthcare, we can harness the incredible power of digital channels and technologies to **improve patients' lives and the healthcare services they use**.

Central to these discussions was the impact of COVID-19, and the new opportunities that have arisen to ensure that patients continue to benefit from digital engagement opportunities.

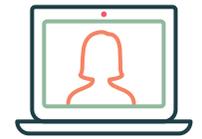
EPIS 2020
at a glance...



Over **250**
attendees...



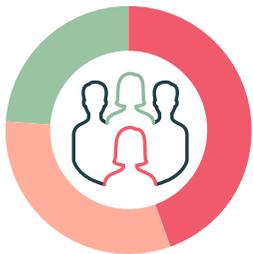
across **40**
countries...



29 interactive
breakout sessions

Recommendations from the EPIS community on how to ensure that patients continue to benefit from digital engagement opportunities:*

Patient Organisations¹



- 28%** Create a **national, digital patient platform** that is simple to use, and can be used for education, training, meetings, and online consultations with healthcare professionals
- 20%** Educate patients on **digital health literacy** including the use and benefits of digital health solutions
- 15%** Make **digital innovation a political and societal priority** that is centred around improving quality of life for patients, not technology companies and healthcare organisations

Health Professionals²



- 27%** Implement **standardised digital health platforms** used by both health professionals and patients (e.g. for teleconsultation, health records)
- 24%** Help patients **interact with health services/professionals digitally** by improving access, training and education for digital solutions
- 19%** **Humanise and adapt digital healthcare** so patients and health professionals are more comfortable using it

Policy Makers³



- 31%** Provide a **central digital health literacy educational tool** which can be utilised by patient organisations, and distributed to patients and health professionals, so that they can better utilise existing tools
- 19%** Make it **easier for patients to interact with their health professionals or health service directly**
- 17%** Create **one centralised national telemedicine system** with virtual clinics

Technology Developers⁴



- 43%** **Co-create digital solutions** with patients and health professionals from the early stages of development, to ensure optimal experience and accessibility
- 14%** Ensure the **digital tool being developed is relevant to patients** and is meeting a specific unmet need
- 11%** Establish **clear objectives for the co-creation process** from the onset and actively seek feedback from different stakeholders throughout the development process
- 11%** Create a **legal framework** which protects both patient communities and organisations, and data from projects

* These recommendations were developed during breakout sessions that took place on the 5th November 2020, in participants' local language at the EPIS 2020 Summit.

Full recommendations per stakeholder, submitted by patient representatives in attendance at the EPIS 2020 Summit (5th November) during the interactive breakout sessions:

Patient Organisations

1. Creation of a national simple digital patient platform (for education training, meetings, online consultation with HCPs) – *Albania*
2. Digital capability building for patients, caregivers, and the community – *Middle East and Africa*
3. Make digitalisation a political & societal priority to improve QoL of patients (and not to drive profits for Tech companies & HCO) – *Belgium*
4. Organise a round table with HCPs & the health providers to commence a dialogue – *Ireland & South Africa*
5. National internet access and coverage and create digital assistants – *Portugal*
6. Educating patients about the use and benefits of digital health solutions – *Slovenia*
7. Electronic health records in primary care – *Malta*
8. Engaging in quality interactions via multi-channel solution which meet the need of all diverse multilingual patient stakeholders – *Switzerland*

Health Professionals

1. Increase digital health literacy among HCPs through different educational channels (i.e. medical school's curriculum) and participation in digital health forum (i.e. EPIS) – *Cyprus*
2. Facilitate and simplify the interaction of patients with their health services in general and with their health professionals directly: like offering access to free Wi-Fi connection in all health services, carrying out a campaign to promote the use of digital media, informing patients about all the issues they can do digitally or conducting training on the use of digital media – *Spain*
3. Humanise and adapt digital health/ care to the patient context, ensuring the engagement of both HCP and patient, taking into account the digital gap – *Spain*
4. Need for lifelong education of the HCPs and their readiness for the HC digitalisation – *Czech Republic*
5. HCPs should attend trainings on the importance of digitalisation, in order to embrace and use it. Also, they should recommend the existing solutions to the patients – *Romania*
6. Implement standardised platforms used both by HCPs and patients (including for teleconsultation, personal data health records) – *France*
7. HCPs can organise a task force in their department to reach out patients and assure they are informed and trained on how to use digital communication platforms – *Portugal*

Policy Makers

1. Enabling the implementation of standards of treatment into intervention in the environment of outpatient software of physicians – *Slovakia*
2. Facilitate and simplify the interaction of patients with their health services in general and with their health professionals directly – *Spain*
3. Equal and global access to the digital innovation and platform (video counseling) – *Italy*
4. One centralised national telemedicine system with virtual clinics – *Adriatic Cluster*
5. Education is needed to both sides, towards HCPs and patient organisations. A good central educational tool and content to all PAGs in the country to be further distributed among patients would be of big support to better utilise existing tools – *Hungary*
6. Policy makers should invest in training to an extended list of age groups for the efficient use of technology – *Greece*
7. Right of access to digital consultation (store and forward, videochats) of health care professionals, ensuring safety, data protection, usability, technical quality – *Germany*

Technology Developers

1. Make sure you co-create digital solutions with patients AND Healthcare professionals at early stages and proactively in order to guarantee full benefit, optimal accessibility and fair ownership of data – *Global/EU*
2. Early, sustainable involvement of PAGs / patient community on a peer-to-peer level to understand needs, decrease barriers & ensure reimbursement – *Germany*
3. The possibility to be easy replicated by other users/ countries protected by the copyright, of course – *Romania*
4. Guarantee patient data privacy and security, including scientific insights and evidence – *Bulgaria*
5. Establish clear objectives and targets early through an active listening and feedback from the different stakeholders with the opportunity of a unique platform usable by the various SHs – *Italy*
6. It's all about patient relevance and answering a certain need. Tech developers need to ensure what they are developing is matched to the unmet need for that specific audience – *Global/EU*
7. The creation of legal framework protecting both the patient communities and patients organisations, as well data coming from the projects – *France*

Footnotes

1. The top three recommendations outlined for patient organisations, represent those which received the most votes from 149 patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020. 2. The top three recommendations outlined for health professionals, represent those which received the most votes from 144 patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020. 3. The top three recommendations outlined for policy makers, represent those which received the most votes from 145 patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020. 4. The top four recommendations outlined for technology developers, represent those which received the most votes from 148 patient community representatives participating in the voting during the EPIS 2020 Summit, 5th November 2020.

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