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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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A new 'Call to Action' has been published by the European Patient Innovation Summit (EPIS) Steering Committee, calling for multiple stakeholders to ensure patients have a voice in the future of digital health solution development.

It will take the united efforts of all stakeholders to ensure the patient voice is stronger in digital health solution development,

Patrick Little, European Migraine & Headache Alliance (EMHA), Ireland

The new call to action challenges all parties involved in the development of digital health solutions to act now to ensure the patient voice is incorporated into the development of digital health solutions, by taking the following actions:

- **Technology developers**: To establish a dialogue with patient communities to understand their needs and involve patients end-to-end in development, so any potential issues are considered early in the process (i.e. with accessibility).
- Healthcare professionals: To be curious and open to the potential of digital health solutions for their patients, embracing their use in daily practice, and to share expertise to ensure clinical questions are considered during development.
- **Pharmaceutical companies**: To involve patients end-to-end in development, exploring ways digital health solutions can better capture the patient experience, so better solutions can be developed for those patients.
- **Policymakers**: To support uptake of digital health solutions that have the greatest impact on patients' lives and, at the same time, address issues relating to data-sharing, making it easier for patients to share their data.
- **Patient advocates**: To develop common solutions to shared problems with the use of digital health solutions, and to increase knowledge of digitization in healthcare to contribute as effectively as possible to their development.



New European Patient Innovation Summit call to action is available online

We hope the 'EPIS Call to Action' will be used across Europe to push for the development of digital health solutions that deliver the most benefits for patient. Any digital health solution should surely start with the patient at its heart, to understand how it can provide the most value.

Stanimir Hasardzhiev, National Patients' Organization, Bulgaria

EPIS was established in 2016 as a platform for patient advocates from across Europe to discuss all aspects of digital health. EPIS is an annual event organized and funded by Novartis, using an innovative multi-site and multi-lingual format, enabling patient advocates from across Europe to learn more about developments in digital health and discuss how to embed a stronger patient voice within the digital health ecosystem.

In 2019, more than 400 patient advocates from different disease areas – along with the EPIS Steering Committee made up of European patient organization representatives – came together across 18 hubs, to:

- develop a common understanding on what digital health is and why it is important for patients
- open a dialogue among different stakeholders about the key challenges faced in digital health today and how these can be addressed
- agree ways in which patients can have a voice in the future of digital health.

The resulting 'EPIS Call to Action' has been co-created by 10 Steering Committee members from seven European countries, summarizing consensus reached by the diverse EPIS patient community and an expert panel at the 2019 event. It builds on recommendations published in the EPIS 2018 Position Paper (PDF 0.8 MB), supporting stakeholders to act to make these recommendations a reality.

Bringing together all of the stakeholders involved in digital health solution development may be challenging. To make sure this multi-stakeholder Call to Action is followed, we need a guiding governance framework, that sets out clear roles and responsibilities; defines concrete ways that the patient should be involved in the end-to-end development of digital solutions; and ensures dialogue between interested parties remains open to finding solutions to implementation barriers, like financial resources.

Birgit Bauer, European Multiple Sclerosis Platform (EMSP), Germany

Additional Resources

EPIS 2018 Position Paper (PDF 0.8 MB)

European Patient Innovation Summit recommends increasing the impact of digital technologies

European Patient Innovation Summit publishes a position paper on Digital Health from a Patient Perspective with recommendations on digital health.

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