Patients in the Digital World: the EPIS Call to Action

Call to Action and Report from EPIS 2019

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Healthcare is entering a new era. There is no longer a reliance on medical treatment only, but a growing focus on the complex healthcare systems that lie 'beyond the pill' and ways in which digitalization, technology and data might be used to transform patients' lives. Since 2016, the European Patient Innovation Summit (EPIS), a partnership between Novartis and several European patient organizations, has provided a platform for patient advocates to discuss and reach consensus on aspects of digital health.

The EPIS format harnesses the power of technology to facilitate connectivity and create a sense of community between patient advocates across Europe. It provides a unique opportunity for patient advocates to come together, breaking down challenging linguistic barriers to discuss common problems and identify common digital health solutions.

In 2018, EPIS participants achieved consensus on a series of recommendations on different aspects of digital health, which were published in a Position Paper, link below. The fourth annual EPIS event, which was held on 7 November 2019, brought together more than 400 patient advocates, representing different disease areas in 18 European hubs*, to discuss how to make these recommendations a reality.

Using EPIS' innovative multi-hub and multi-lingual format, the EPIS community identified concrete actions to ensure that patients:

• have a voice in the development of digital health solutions

• have access to digital health solutions that can improve their lives.

These concrete actions are outlined in **the EPIS Call to Action,** which we hope will be used by patient advocates throughout Europe to push for the utilization of digital health solutions that can deliver the most benefits for patients.

This report includes the EPIS Call to Action and provides a summary of the EPIS 2019 proceedings.

*Participating EPIS hubs across Europe: Albania, Belgium, Bulgaria / Macedonia, Croatia, Cyprus, Czech Republic / Slovakia, France, Germany, Greece, Hungary, Ireland, Italy Lithuania, Malta, Portugal, Slovenia, Spain, Switzerland.

EPIS 2018 Position Paper: https://www.novartis.com/sites/www.novartis.com/files/epis-position-paper.pdf

The EPIS
Call to Action

In 2018, participants at EPIS achieved consensus on a series of recommendations to transform development and uptake of digital health solutions – with the goal of benefiting patient wellbeing – and published these in a **Position Paper*.** Now, the EPIS Community call on the following stakeholders to take action to ensure that the EPIS 2018 recommendations become a reality.

Technology developers

Establish a dialogue with different patient communities, to understand their biggest unmet needs and how different technologies could be used to address these needs.

Involve patients from the beginning to the end of the development of digital health solutions, where patients are the end-user or beneficiary. Involve other end users, like healthcare professionals, if they are also going to use the solution or recommend the solution to patients.

Ensure that any issues with accessibility or understanding are taken into consideration early in digital health solution development.

"Patients have not been involved enough to date – user experience (UX) and design should be intuitive, and technology should be designed to gather data that matters most to patients"
Cecile Ollivier, Chief Operating Officer, Aparito, France

Healthcare professionals

Be curious about the potential of digital health solutions to help meet patients' needs and be open to using technologies that have been shown to help improve patients' health and wellbeing.

Engage with other stakeholders on the development of digital health solutions that will be used by patients to ensure that clinical aspects are taken into consideration during the development process.

Embrace the use of electronic health records (EHR) in daily practice and push to break down organizational and technical barriers to the optimal implementation of EHR in health services across Europe.

"Data science and digital health can help us deliver on the promise of connectivity",
Sander Ruitenberg, Worldwide Head of Digital Solutions for Immunology, Hepatology & Dermatology, Novartis, Switzerland

Pharmaceutical companies

Explore ways in which digital health solutions can be deployed to better capture the patient experience of a medicine and the burden of living with a given condition.

Involve patients in the end-to-end development of digital health solutions.

Continue to connect the dots between the different data that companies collect from various sources, in order to generate insights that can identify innovative solutions to patient problems.

"Patients want to access their data, but data privacy is also a major concern: more involvement of patients is needed – this is still poor but progressing"
Philippe Kolh, Chief Information Officer and Chairman of the Department of Medico-Economic Information, University Hospital of Liège, Belgium

Policy makers

Support the uptake of digital health solutions that have been shown to have the greatest impact on patients' lives and wellbeing.

Reconsider policies relating to medical device assessment and recommendation, to decrease the time it takes for digital health solutions to come to market, so that when they do, they are current and relevant.

Change the way that healthcare is financed in order to, for example, stimulate the more widespread use of EHR.

Address patients' concerns about data-sharing without making it too difficult for patients to share their data.

"As patients, we have years of experience of our disease and know what could be done to make it better – we don't have to do the technology ourselves, but we must make sure the people who do, know what we want – and we must explain this very clearly",
Birgit Bauer, European Multiple Sclerosis Platform, Germany

Patient advocates

Join forces with other interested patient advocates to develop common solutions to shared problems associated with the use of digital health solutions.

Increase knowledge of digitalization in healthcare in order to effectively contribute to digital health solution development.

Seek out opportunities to engage with all stakeholders in the digital ecosystem, so that they better understand the patient perspective and will be more likely to engage early and systematically with patients in the development of digital health solutions.

To make this multi-stakeholder Call to Action a reality, there is the need for a governance framework that:

- Sets out clear roles and responsibilities for the different stakeholders involved in the development and utilization of digital health solutions;
- Defines concrete ways in which patients should be involved in end-to-end development of patient-focused digital health solutions; and,
- Ensures dialogue between interested stakeholders to ensure that solutions are found to implementation barriers, including financial resources.

*EPIS 2018 Position Paper: https://www.novartis.com/sites/www.novartis.com/files/epis-position-paper.pdf

Patients in a Digital World
Meeting outcomes from EPIS 2019

The objectives of the fourth annual European Patient Innovation Summit (EPIS) were as follows:

1. Develop a common understanding about what digital health is and why it is important for patients
2. Open a dialogue among different stakeholders about the key challenges faced in digital health today and how these can be addressed
3. Agree ways in which patients can have a voice in the future of digital health.

On the day, various formats were used to encourage exchange of information and consensus-building: virtual keynote speaker presentations, panel discussions, local breakout sessions, and interactive voting.

The outcomes from the summit per objective are detailed below.

1. Develop a common understanding about what digital health is and why it is important for patients

Local breakout discussions were held in 18 hubs across Europe to develop a common understanding about what digital health is and why it is important for patients. The breakout discussions were designed to:

- identify the most beneficial technologies and those with the greatest concerns, and
- to provide clarity on the key benefits and concerns associated with these technologies.

Local discussions were supported by a glossary of terms detailing ten technologies often used in healthcare (see Appendix 1).

Feedback from the hubs was shared and interactive voting was conducted to reach consensus among the EPIS participants. From this voting, a stark duality was observed – with attendees across Europe identifying electronic health records both as the most beneficial and the most concerning digital technology category individually and in their country (Table 1). Commonly cited benefits and concerns for the most voted-upon technologies (electronic health records and social networking) are given in Tables 2 and 3.

Table 1: Most beneficial and most concerning technology categories

Most beneficial technology category (votes: 187)	Most concerning technology category (votes: 167)
Electronic health records: 71.12% (133)	**Electronic health records: 31.14% (52)**
Health monitoring: 8.56% (16)	Social networking: 28.14% (47)
Social networking: 4.81% (9)	Digital personal assistant: 11.98% (20)

*Top three categories shown; See Appendix 2 for full voting results

Electronic health records

An electronic health record, or electronic medical record (EMR), is the systematized collection of health information about patients in a digital format. These records can be shared across different healthcare settings. Table 2 summarizes potential benefits and concerns associated with EHR.

Table 2: Benefits and concerns associated with EHR

Benefits	Concerns
• A single platform with complete, personalized patient information • Accessible anytime, anywhere • Transparency for all stakeholders • Enhanced multi-disciplinary interaction, leading to improved service continuity • Information transferable across hospitals/borders • Saves time, costs and resources (i.e. reduced procedure duplication) • Risk reduction (i.e. medicine interactions) • Early detection and avoidance of complications • Improved medication adherence • Facilitation of data collection in research/ real-world evidence	• Data privacy, loss of data • Technical problems • Data ownership • Data sharing rules and algorithms

Social networking

Social networks are online patient communities that enable patients to share information, improve their understanding of their condition and support one another. Table 3 summarizes potential benefits and concerns associated with social networking.

Table 3: Benefits and concerns associated with social networking

Benefits	Concerns
• Peer support, feeling connected • Sharing of information • Interaction and co-creation • May reduce isolation / increase inclusion	• Lack of face-to-face interaction • Questions around credibility of content, i.e. fake information that could mislead • Possibility of 'trolling' • Data privacy • Lack of transparency around data sharing • Exclusion of patients • Possible 'nocebo' effect

Patients in a Digital World
Meeting outcomes from EPIS 2019

2. Open a dialogue among stakeholders about the key challenges faced in digital health today and how these can be addressed

EPIS participants took part in a 'Question Burst' exercise[1] to identify potential solutions to challenges faced in securing a stronger voice for patients in digital health solution development.

First step: identifying the most important questions

Participants identified the most important questions that need to be asked about the challenge of securing a stronger voice for patients in digital health solution development. The questions that were most suggestive of potential solutions were submitted by the hubs to the EPIS app.

Some questions focused on how to involve all patients in digital health solution development, ensuring they are sufficiently empowered and educated to have an impact. Other questions focused on how to create a robust governance framework that would support patient involvement, ensuring that listening to the patient voice becomes a mandatory part of the development process.

Further questions looked at identifying points in the development process where patient involvement is most important. In addition, the challenge of ensuring the needs of all patients are represented (across disease types and countries) was highlighted.

Some hubs looked beyond patient involvement in the development of solutions, to ask how patients can better influence the uptake of important solutions.

Second step: prioritizing the most important questions

Participants were asked to vote on which questions they thought were most important and deserved further exploration. It was agreed to focus on the following questions and to explore what actions could be taken on the basis of these:

- **How do we involve all patients?**
- **What do we need to do to ensure that patients become the most important voice in the decision-making process regarding digital health solutions and data privacy?**
- **How do we create a robust governance framework that includes the participation of different types of patients in the development of technologies so that tools created are fit for purpose?**

A list of all the questions identified by the different hubs can be found in Appendix 3.

Third step: action-focused panel discussion

A multi-disciplinary panel of representatives from different stakeholder groups was asked to reflect on the identified questions and identify which actions they thought could be taken to secure a stronger patient voice in the development of digital health solutions.

Their ideas are summarized below and reflect actions that can be taken by their respective stakeholder groups.

Patient representative

Birgit Bauer, European Multiple Sclerosis Platform, Germany

Patients have years of experience of their disease and know what could be done to make it better – it is therefore important that the people who develop digital solutions know what patients really want.

There are many ways technology could support patients' lives, rather than making it more complicated.

- EHRs and symptom trackers can help to explain the course of a person's disease
- Pharmacy apps could save the patient time
- Telemedicine means patients can be cared for remotely, and can save time
- Electronic prescriptions save time and in some cases money for patients
- Training tools could help improve cognitive function
- Patients can connect through online tools if they have simple questions

Identified actions – patient representative perspective
- Bring patient communities together, recognizing common problems and goals
- Remain curious and open to engagement with all other stakeholders
- Improve understanding of technology, making it possible to come to the table and have conversations with other stakeholders

1. Harvard Business Review. *Better Brainstorming*. Available at: https://hbr.org/2018/03/better-brainstorming (accessed February 2020)

Patients in a Digital World
Meeting outcomes from EPIS 2019

Healthcare professional

Dr. Philippe Kolh, Chief Information Officer and Chairman of the Department of Medico-Economic Information, University Hospital of Liège, Belgium

Technology is not the end goal; it is a tool to get there. The end goal is patient health: managing each person's health in the best possible way and - at the same time, as much as possible - managing healthcare costs. To achieve this in an increasingly digital world, structure, financial resources, and identification of patients' needs are vital.

- By using big data, it is increasingly possible to target treatments to a specific patient rather than using data published in large clinical trials, from which a large proportion of patients have usually been excluded

- Physicians and nurses should be involved in conversations around digital development – if tools are developed by patients and 'tech people', the healthcare professional may not want to use them, due to burden of use

- The way healthcare is financed must change. Patient organizations can be involved in lobbying politicians and the people who finance the deployment of technologies for healthcare.

Identified actions – healthcare professional perspective
- Create a clear governance framework
- Nominate a good leader and a Steering Committee to decide what must be done and the methodology
- Create a roadmap and show how we are going to get there – within budget

Digital entrepreneur

Cecile Ollivier, Chief Operating Officer, Aparito, France

Patients often have anxieties around technology because they have not been involved enough in the development process. The patient should be the first person involved in this process: how can technology help you in your daily life?

In the digital world, everything progresses at speed, so without patient involvement and compliance, problems quickly become obvious. For example, while EHR is widely acknowledged as important, data privacy and standardization are still big challenges.

Wider discussions like these can be triggered at government level, with all stakeholders involved, if there is a common goal.

Identified actions – digital entrepreneur perspective
- Lay out common principles for patient involvement in every project
- Ensure that no project aimed at patients is designed without patients at the table

Industry digital expert

Achim Plueckebaum, Head GDD Data42, Novartis, Switzerland

Stakeholders should not wait to open a dialogue – understanding one another requires discussion. Complex and innovative things are happening, so this dialogue needs to get stronger moving into the next decade of innovation.

Patients must always be able to opt in or out – then patients and associations can say they are in, because they believe there is something to add, or they can opt out.

Identified actions – industry expert perspective
- Continue to connect the dots between data - the technology behind EHR is quite basic; the complexity lies in connecting these dots
- Be curious – technology may seem overwhelming and inaccessible, but with exposure, things become easier and more understandable
- Remain open to engagement with all other stakeholders – industry, healthcare professionals, technology developers and patients

Patients in a Digital World
## Meeting outcomes from EPIS 2019

3. Agree ways in which patients can have a voice in the future of digital health
The EPIS 2019 consensus - concrete actions that can be implemented across Europe

Based on the multi-stakeholder panel discussion, nine key actions that can be taken to ensure a strong patient voice in the development of digital health solutions were identified (Table 4). EPIS participants were asked to vote on which actions they thought would be most important.

The majority thought that the creation of a governance framework that sets out roles, responsibilities and procedures to ensure continuous, effective and efficient inclusion of patients (and other end users) in digital technology development was the most important action. Such a framework would help ensure that patients were in the driving seat and could hold other stakeholders to account.

Table 4: Key actions that can be taken to ensure a strong patient voice in the development of digital health solutions
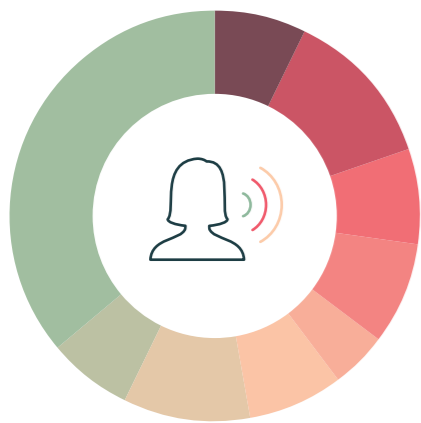
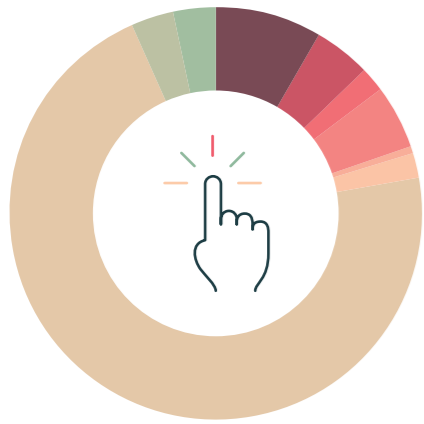| Key	Option	Votes	%
	Need to have representation of all patient views	11	7.33%
	Secure European funding	19	12.67%
	Learn from each other and work together to push for a seat at the table	11	7.33%
	Build patient skills in technology	12	8%
	Increase dialogue between stakeholders	7	4.67%
	Raise tech developers' awareness about benefits of involving patients	11	7.33%
	Involve all stakeholders in defining needs	15	10%
	Promote user-centric design	10	6.67%
	Build a governance framework for involvement of patients	**54**	**36%**

NB: Number of votes: 150

Appendix 1:
Glossary of digital health solutions

| Technology	Description
Health monitoring	Digital platform or wearables that facilitate the collection of data on different aspects of health including quality of life and symptom experience. Patients can either input data to a digital platform or use devices worn on the body (wearables). Data can be shared real time with health professionals so that rapid action can be taken if there is a deviation from the norm. Data can also be shared with health professionals during a consultation. Platform can enable real world evidence of a disease experience to be collected
Online consultation with health professionals	Digital platform where patients can have an online consultation with a doctor or psychologist and have follow up consultation via SMS or email
Digital administration of care	System that allows patients to make appointments online with hospitals and specialists. Also an online prescription refill system which means that prescriptions are sent to the patients local pharmacy without having to get a paper prescription
Social networking	Online patient communities that enable patients to share information, understand better their condition and support each other
Medication support	Apps that help patients schedule their medications, remind them to take medications and when it's time for a refill and inform them if there is an interaction between their medication
Digital personal assistant	Smart algorithm-powered (artificial intelligence), text or voice-based interfaces (chatbots) that can provide patients with information, help triage problems the patient is experiencing and provide initial advice and support to manage a problem
Electronic health records	An electronic health record (EHR), or electronic medical record (EMR), is the systematized collection of health information about patients in a digital format. These records can be shared across different health care settings
Digital education tools	Education tools including games (gamification) that help empower patients
Smart devices to support independent living	Smart devices that help patients manage a disability and live as independently as possible

Appendix 2:
Voting results - benefits and concerns

Voting results: What is the most beneficial technology?

Key	Option	Votes	%
1	Health monitoring	16	8.56%
2	Online consultation with health professionals	8	4.28%
3	Digital administration of care	4	2.14%
4	Social networking	9	4.81%
5	Medication support	1	0.53%
6	Digital personal assistant	4	2.14%
7	**Electronic health records**	**133**	**71.12%**
8	Digital education tools	6	3.21%
9	Smart devices to support independent living	6	3.21%

NB: Number of votes: 187

Voting results: What is the technology with the most concerns?
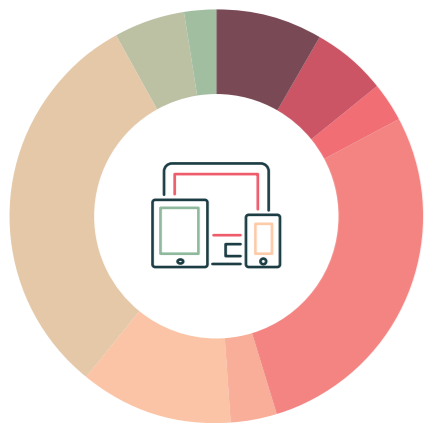
Key	Option	Votes	%
1	Health monitoring	14	8.38%
2	Online consultation with health professionals	10	5.99%
3	Digital administration of care	5	2.99%
4	Social networking	47	28.14%
5	Medication support	6	3.59%
6	Digital personal assistant	20	11.98%
7	**Electronic health records**	**52**	**31.14%**
8	Digital education tools	9	5.39%
9	Smart devices to support independent living	4	2.4%

NB: Number of votes: 167

Appendix 3:
Key questions identified in each hub

- **Portugal:** How can we make sure that we involve ALL the patients? (69 likes)

- **Malta*:** How are we going to raise awareness, educate and empower? (39 likes)

- **Ireland:** How can patients and patient groups speed up the problem of EHR implementation? (34 likes)

- **Slovenia:** How to ensure that inclusion of PAGs into finding solutions won't be an option but an obligation? (28 likes)

- **Albania:** How can we make sure that patient advocacy groups are legally bound to be part of the development process for digital health solutions? (28 likes)

- **Belgium:** How can patients identify needs and be in the driving seat? (27 likes)

- **France:** How to take into account the individual, sociological, and demographical particularities and patients' experiences? (25 likes)

- **Italy:** What training and expertise is needed by all stakeholders (including patients and patient advocates) in order to positively collaborate? (25 likes)

- **Cyprus:** At which stage of development of digital health solutions should patients be involved; how do we ensure patients are equipped and empowered for that; and how is this involvement ensured and funded for all disease areas? (22 likes)

- **Hungary:** How is it possible to develop general European solutions, and apply them at different country levels and in a personalized way? (22 likes)

- **Czech Republic / Slovakia:** Who will pay for it? (20 likes)

- **Switzerland:** How do we fully co-create with patients to improve their quality of life? (17 likes)

- **Germany:** Which other national health portals exist in different countries, who is involved and how are they structured? (16 likes)

- **Greece:** In which ways can patients be involved in the development of digital health solutions? (13 likes)

- **Bulgaria / Macedonia:** How could policy makers be more involved and forced to go for digital health solutions? (11 likes)

*NB: The Malta hub entered their question twice, so votes for both have been combined here.