EUROPEAN
PATIENT
INNOVATION
SUMMIT
2017

REALISING THE CONNECTION
OF DIGITAL TECHNOLOGIES

EXECUTIVE SUMMARY

EUROPEAN PATIENT INNOVATION SUMMIT (EPIS) 2017

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European Patient Innovation Summit (EPIS) 2017

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REALISING THE CONNECTION
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The second European Patient Innovation Summit (EPIS) 2017 explored how digital technologies are revolutionizing healthcare and set out to assess ways to ensure patients can have a more impactful voice in healthcare decision-making. The Summit agenda was developed in collaboration with a Steering Committee of leading patient advocates, to build on the recommendations that came out of EPIS 2016, and focused on the key question of how the systematic resistance to patient input across the medicines life cycle can be addressed. The Summit consisted of two digital technology expert presentations, a panel discussion and an Ideathon. The Ideathon focused on brainstorming innovative ideas, through which patients can have more involvement across the medicines life cycle, and led to the generation of new and disruptive European solutions to bring about the changes needed. It provided an inspiring atmosphere for critical thinking, allowing participants the space and time to contemplate and deliberate ideas with their colleagues in a dynamic environment. The Summit included 16 European hubs with a central hub in Dublin, and had outreach to approximately 250 face-to-face participants throughout Europe, with many more joining using the livestream platform.

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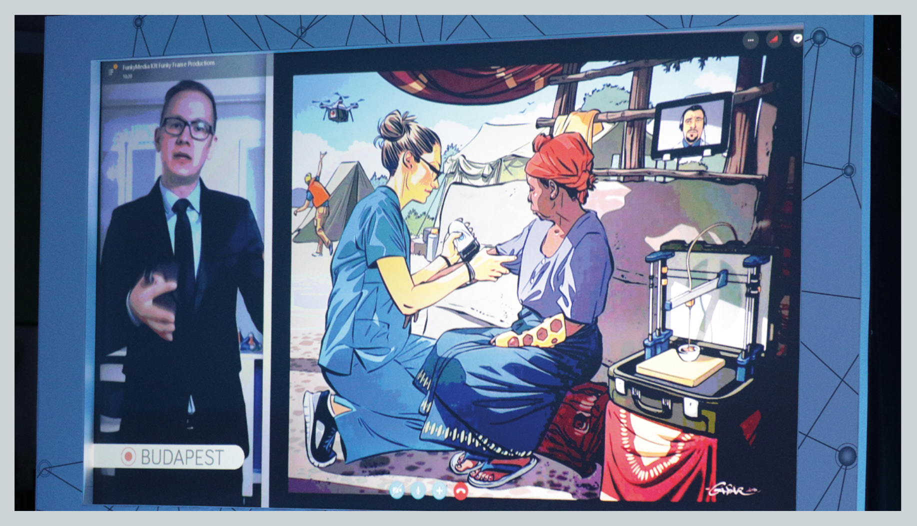
SCIENCE FICTION IN HEALTHCARE – DR BERTALAN MESKÓ

Dr Bertalan Meskó, the Medical Futurist, spoke about his vision for the future, 'science fiction' technology that would challenge the status quo and transform the involvement of patients in their treatment, bringing healthcare into the 21st century. Patient-driven design is vital, patients must be asked about their needs and desires, and partner more closely with doctors to manage their health. Patients could create their own devices, like diabetic patients in the USA – creating DIY systems to help prevent sudden drops in blood glucose while sleeping. Technologies are driving change that will integrate the potential of digital tools into the doctor's office. Policy makers need to be at the front of innovation, and patients need increased digital literacy, so that data generated by new technology can be utilized.

> *"We have to learn how to be exceptional human beings with skills that help us live healthier and longer lives... Only digital health can help us bring technologies for healthcare today so that empathy and the human touch will always be in the spotlight of the doctor-patient relationship."*

Privacy and consent are problems for many digital health technologies and individuals need to decide how much personal data they are willing to share in the quest for longer, healthier lives. Ownership of data has shifted to the forefront of patient engagement strategies. To increase the uptake of technology in everyday life the speed of regulatory processes needs to improve, though balanced with maintenance of the need for patient safety.



DIGITAL REINVENTION: RETHINKING HEALTHCARE – HEATHER FRASER, IBM INSTITUTE FOR BUSINESS VALUE

Heather Fraser gave an engaging presentation on how the old system of drug development is changing into a healthcare 'ecosystem' with the patient at the center. With an aging population, technology is growing and access to treatments is expanding, and this ecosystem consists of connections between several industries and the patient.

At present, only 1% of the world's available data is being analyzed, and that data is rapidly growing in volume, variety and complexity - only a very small proportion of this data are used to aid healthcare decision-making. IBM is using cognitive computing to increase the accuracy of clinical trials, allowing doctors and nurses to engage with patients around the clock, to improve patient safety and clinical trial results. Some examples of this are cutting the patient screening time for trial eligibility from almost 2 hours to less than 30 minutes; analyzing patient Facebook posts to improve their engagement in clinical trials and increasing the number of patients that stay enrolled in trials; and real-time monitoring to improve care for diabetic patients.

The healthcare industry has seen significant disruptions in the last three to five years

Shifting demographics and growth in chronic and lifestyle diseases…

has increased pressure on healthcare systems around the world

Technological advancements in healthcare…

has made healthcare more cost-effective and with better and more successful outcomes

Transition to value-based reimbursement…

has created affordable, better quality care at lower reimbursement rates; from wellness and pre-emptive treatment to acute care for chronic diseases

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PANEL DISCUSSION: OVERCOMING RESISTANCE TO ACCEPTING THE VALUE OF THE PATIENT VOICE – EXPLORING DIFFERING PERSPECTIVES

A clinician (Dr Raj Sengupta), statistician (Karen Facey), pharmaceutical company representative (Laura McKeaveney) and patient advocate (Nicola Bedlington) discussed the reasons why there is resistance to accepting the value of the patient voice across the medicines life cycle as well as solutions to overcome this.

From a clinician's perspective, there is very little time to interact with patients and limited trial evidence on how to include digital technology into everyday practice. Historically, the nurse and doctor have been perceived as the client and there remains a need to build a grassroots movement around the importance of patients in the drug development process. Another barrier to patient involvement is the perception of the patient voice as anecdotal and non-rigorous, not fitting into accepted scientific methodologies. More investment is needed to support research that provides these data.

Doctors are worried about opening the data floodgates – if they ask their patients more questions they may be overwhelmed by information. Patients have a different perspective to doctors, and their ongoing feedback and insight would improve clinical trials.

> "We are missing out on huge volumes of data that is coming from patients for clinical studies."

Novartis is committed to overcoming the cultural resistance to the patient voice by building on their existing experience of working with more than 1,300 patient groups around the world and across a range of diseases. There are continued efforts to build relationships and trust with patient organizations with conversations built on mutual respect and listening. *Novartis is creating a plan that builds on the belief that patients must be listened to and heard.*

PANEL DISCUSSION: OVERCOMING RESISTANCE TO ACCEPTING THE VALUE OF THE PATIENT VOICE – EXPLORING DIFFERING PERSPECTIVES

From the decision-making bodies' perspective, it was explained that the scientific background and methodology of HTA is a barrier to patient involvement in the medicines life cycle. There is a need to *shift from talking about the 'patient voice' to the 'patient perspective'* supported by research. This will enable us to get to the heart of the value of clinical assessments and outcomes, and to identify the real-life effects.

From a patient advocate's perspective, a framework for change, created by patients and pharmaceutical companies is essential to increase patient engagement. It was argued that resistance to the patient voice is not the main problem. There is acknowledgement that patient engagement is important and the necessary way forward. The widespread issue is a lack of knowledge and resistance to change within the pharmaceutical industry, with few systematic and structured approaches to involving patients. A framework for change is essential, one created by patients and pharmaceutical companies together to increase patient engagement. Three key arms for inclusion of the patient voice were outlined: a systematic framework, a long-term plan and further patient education.

The moderator of the panel discussion commented on the various perspectives given during the panel discussion and closed the session by stating that some patients would say:

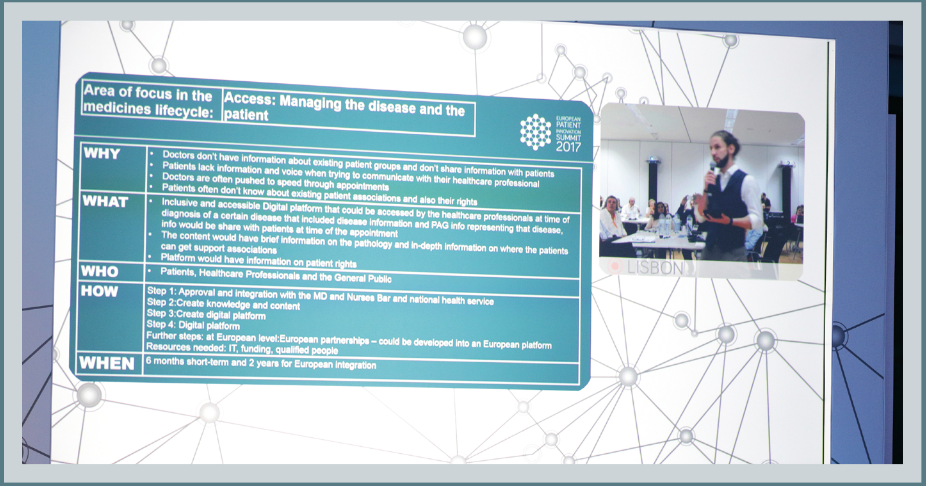
> "I am the expert in my condition. No one knows my condition the way I experience it, better than I do."

IDEATHON

Each European hub focused on an area of the medicines life cycle to identify a solution to meeting the challenge of “the systematic resistance to accepting the value of the patient voice”. Once ideas were consolidated at the hubs they were submitted to the Steering Committee of members of different patient organizations who acted as an independent jury. During an hour of analyzing the Ideathon solutions, the independent jury scrutinized, discussed and debated the various merits and flaws in the solutions presented. It was an exciting session, which provided a lot of food for thought, and highlighted the creativity of the Ideathon process.

Norway, Germany and Portugal were finalists from hubs that had livestreaming, but could also interact live with the central Dublin hub. Rapporteurs in Norway, Germany and Portugal presented their solutions live back to all the hubs, and a vote commenced for all hub participants to determine the winning solution – Portugal was the winning country!

Portugal proposed a solution to the problem of accessible information for doctors and patients. The proposal was about building a digital directory of patient organizations and patient rights for doctors and patients. This digital platform would be available to doctors and nurses and include specific information about available patient groups for a particular disease; this information could be shared with the patient when they receive their diagnosis.



Area of focus in the medicines lifecycle:	Access: Managing the disease and the patient
WHY	• Doctors don't have information about existing patient groups and don't share information with patients • Patients lack information and voice when trying to communicate with their healthcare professional • Doctors are often pushed to speed through appointments • Patients often don't know about existing patient associations and also their rights
WHAT	• Inclusive and accessible Digital platform that could be accessed by the healthcare professionals at time of diagnosis of a certain disease that included disease information and PAG info representing that disease, info would be share with patients at time of the appointment • The content would have brief information on the pathology and in-depth information on where the patients can get support associations • Platform would have information on patient rights
WHO	• Patients, Healthcare Professionals and the General Public
HOW	Step 1: Approval and integration with the MD and Nurses Bar and national health service Step 2:Create knowledge and content Step 3:Create digital platform Step 4: Digital platform Further steps: at European level:European partnerships – could be developed into an European platform Resources needed: IT, funding, qualified people
WHEN	6 months short-term and 2 years for European integration

IDEATHON

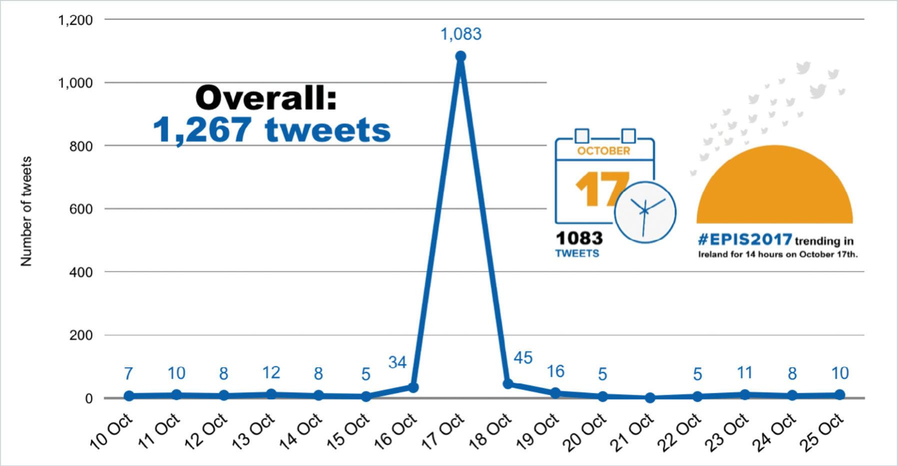
The platform would also contain in-depth information for patients and the public regarding specific diseases and patient rights. The directory would be created with input from healthcare providers and the National Health Service along with patient associations. The proposed timeframe for development of this platform is 6 months to create an initial version for Portugal, with a goal of spreading the platform across Europe within 2 years.

The Czech Republic and Slovakia, Austria and Hungary who accessed the Summit only through livestreaming, also submitted Ideathon solutions and the independent jury chose an additional winning entry from the Czech Republic and Slovakia. The solution proposed communication training for medical students, along with regular meetings between medical schools and patient groups, in order to improve patient-physician communication.

Post-Summit, participants could spend extra time evaluating the solutions and could vote online for the Ideathon best online solution, Hungary were the winning hub. In Dublin, the Summit was brought to a close by Marie-Claude Meylan, Ambassador of Switzerland, before an evening reception for attendees.

POST-EVENT FEEDBACK AND SOCIAL MEDIA EVALUATION

Sixty-one meeting participants gave an average score of more than 4 out of 5 when asked about the value of the Summit, relevance to the work of their patient organization, meeting format and whether something new had been learned. Throughout the meeting social media helped amplify the reach of EPIS 2017, at peak activity #EPIS2017 was the second most-tweeted hashtag in Ireland, with 1,267 tweets using the hashtag. Social engagement across multiple channels (Twitter, Facebook, and LinkedIn) achieved 778.8K reach and 3.4M impressions. Key stakeholder groups tweeting about the event were patients, patient organizations, activists and advocates. These groups contributed 38% share of the conversation between them, with experts and academics contributing a further 13%.



Overall, the Summit delivered a technology-rich, innovative, and far-reaching program. Participants were able to build connections across disease communities, and develop new approaches to raising the profile of the patient voice. Novartis is very excited to continue exploring this model of patient engagement, with the first Global Patient Innovation Summit in 2018.

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