

# THEME 6

## THE DIGITAL HEALTH REVOLUTION: HYPE VS. REALITY

### THEME LEADERS:

**Julián Isla**, Data and Artificial Intelligence Resource Manager, Microsoft & Chief Scientific Officer, Dravet Syndrome European Foundation, Spain.

**Justina Januševičienė**, Head of Healthcare Innovation Development Centre, Lithuanian University of Health Sciences, Lithuania.

**Brian O'Connor**, Chair, European Connected Health Alliance, UK/Ireland

### THEME SUPPORT :

**Denis Costello**, Executive Director, CML Advocates Network, Spain.

**Marta Campabadal**, RareConnect Manager, EURORDIS

### THEME DESCRIPTION:

This theme examines the technological innovations that are underpinning disruption in medicine and science, as well as the legal, ethical and policy foundations that can frame future outcomes in this area. The theme will also look at how technology can support the social inclusion of people living with a rare disease.

Attendees should come away from this theme with a greater understanding of the role of quality data in technologies such as Artificial Intelligence and how this impacts the development of medicines and delivery of care and other services. The theme aims to question the value of such technological innovations, as well as to show the policy frameworks and ecosystems which patient representatives can involve themselves in, in order to bring the patient's voice to the evolution of policy and ethics in this area.

**SESSION o6o1:** Thursday 14<sup>th</sup> May 2020, 14:45 – 16:15

### **Do we need a New Patient Data Management Model for AI?**

Artificial Intelligence seems to be the holy grail, promising to solve the many challenges faced by the current healthcare system. What do we need in order for models based on Artificial Intelligence to work? The answer: large datasets for training those models. These large datasets have usually been safeguarded by hospitals, the traditional centres of medical care.

But this centralized hospital data model is giving way to a hybrid system, where data is generated not only by the hospital but also by the patient and other sources. In addition we have the problem that certain data (such as genomic data) is too large to be stored within the traditional medical information system based in hospitals.

Perhaps we need new data management models that allow the capture, processing and analysis of medical data generated by various sources. This question is particularly significant for rare disease patients as they often have to visit multiple specialists in different healthcare centres. In this session we will discuss the new data management models we will need, and potential challenges that may arise (medical, regulatory, security, privacy, ethics).

**Chairs:** Denis Costello, Executive Director, CML Advocates Network, Spain

#### **Speakers:**

**Paul Rieger**, Managing Director, Centiva Health, Austria

**Peter Speyer**, Head of Products, data42, Novartis, Switzerland

**Dr. Marco Roos**, GO FAIR, Netherlands

**Nicholas Becker**, AI for Good, Microsoft, USA

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**SESSION o6o2:** Thursday 14<sup>th</sup> May 2020, 16:45 – 18:15

### **Considerations Surrounding the Ethical and Legal Aspects of Data Governance**

The current COVID-19 crisis has brought into sharp relief some of the big challenges on the ethical and legal aspects of data governance, most significantly in the debate on the use contact tracing apps as a key tool in the transition out of lockdown and the management of a 'new normal'. The use of such apps highlights the fragile and complex balance between public and private interests in data, the need to build trust in data governance systems and the need for effective mechanisms for data solidarity. In this session you will hear speakers address all of these issues, providing insights on how the balance between public and private is seen in our rare disease communities as well as about exciting developments in new approaches to making data available for research (Findata) and facilitating data solidarity (Salus Coop).

**Chair:** Dr. Petra Wilson, Managing Director and CEO, Health Connect Partners, UK

#### **Speakers:**

**Dr. Bettina Ryll**, Founder and President, Melanoma Patient Network Europe

**Rosa Juuti**, Senior Specialist, Findata, Finland

**Sandra Courbier**, Social Research Director, Rare Barometer Voices, France

**Joan Guanyabens**, Consultant Health IT and Innovation, Salus Coop, Spain

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**SESSION o6o3:** Friday 15<sup>th</sup> May 2020, 11:30 – 13:00

### **Getting Solutions to Patients Quicker and more Effectively: Are Policy, Procurement and Patients the Enablers or the Obstacles?**

What changes are necessary to get solutions to patients quicker and more effectively? The speakers will share their own experiences and express their own perspectives on whether or not policy, procurement and patients are the enablers or obstacles. This interactive session will seek consensus on concrete actions to overcome any obstacles and map out a way forward.

**Chair:** **Brian O'Connor**, Chair, European Connected Health Alliance, UK/Ireland

#### **Speakers:**

**Prof. George Crooks**, Digital Health & Care Institute, Scotland

**Jaana Sinipuro**, Project Director, IHAN – Human-Driven Data Economy, SITRA, Finland

**Liz Ashall-Payne**, Founder and CEO, ORCHA, UK

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**SESSION o6o4:** Friday 15<sup>th</sup> May 2020, 14:00 – 15:30

### **Technology for inclusion and empowerment**

This session will highlight the possibilities of empowerment and inclusion presented by innovative technology. You will hear about a number of good examples around tech-tools, digital accessibility and policymaking that can be used as means and stepping stones to reach full holistic inclusion.

**Chairs:** **Robert Hejdenberg**, President, Agrenska

#### **Speakers:**

**Dr. Stefan Johansson**, KTH Royal Institute of Technology, Sweden

**Daniel Forslund**, Assistant Regional Council in the Stockholm Region, Sweden

**Allison Watson**, Patient Advocate, Ring2o, UK

**Veronica Popa**, Patient Advocate, Romania

**Ana Neacșu**, Speed (Speech & Dialogue Research Laboratory), Romania

**Tim Buckinx**, Founder and CEO, Epihunter, Belgium