

# 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 o601:** Friday 15<sup>th</sup> May 2020, 14:00 – 15:30

### **Big Data: The Time is Now to Think Big**

Healthcare management becomes much more efficient with the help of big data, reducing the cost of care, enhancing performance measurement, providing the best clinical support, and managing patients. Big Data is vast and not easily manageable. Alongside other technologies, Big Data plays an important role in opening new doors of opportunities. On the other hand, medical data is sensitive and can cause severe problems if manipulated or misused.

This session will focus on the importance of the right data, gathered from trustworthy sources, standardised, obtained, stored and processed in a legal way. The speakers will reveal practical examples of benefits arising from proper engagement of Big Data.

**Chair: Justina Januševičienė**, Head of Health Care Innovation Development, Lithuanian University of Life Sciences

#### **Speakers:**

**Paul Rieger**, Centiva Health, USA

---

**SESSION o602:** Friday 15<sup>th</sup> May 2020, 16:30 – 18:00

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

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

#### **Speakers:**

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

---

**SESSION o603:** Saturday 16<sup>th</sup> May 2020, 09:00 – 10:30

### **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**, DHI Scotland

Hannu Hämäläinen, Finnish Innovation Fund Sitra

---

**SESSION o6o4:** Saturday 16<sup>th</sup> May 2020, 11:00 – 12:30

### **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 & **Julián Isla**, Data and Artificial Intelligence Resource Manager, Microsoft; Chief Scientific Officer, Dravet Syndrome European Federation (DSEF); Founder and CEO, Fondation 29, Spain

---

**SESSION o6o5:** Saturday 16<sup>th</sup> May 2020, 14:30 – 16:00

### **Tech 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.

**Chair:** **Robert Hejdenberg**, President and CEO, Agrenska, Sweden