

## ECRD 2024 THOUGHT LEADER SESSION

### Harnessing Digital Solutions for Rare Diseases

25 April 2024, 12.00-13.15 CET, Online

#### Goal

This workshop aims to facilitate knowledge exchange, foster collaboration, and inspire action towards leveraging digital solutions for the benefit of individuals living with rare diseases.

#### Expected outcomes

- **Increased Awareness:** Participants will be able to describe the unique challenges faced by individuals with rare diseases and explain the potential of digital solutions to address them.
- **Demonstrated Innovation:** Attendees are introduced to innovative digital tools and technologies designed for rare diseases, being able to describe the ways in which diverse approaches can improve patient outcomes and healthcare delivery.
- **Strengthened Advocacy Efforts:** Participants are able to explain the value and necessity for policies, funding, and research initiatives that support the advancement of digital healthcare solutions for rare diseases.

## AGENDA

12.00-12.05 **Introduction** by Jelena Malinina, EURORDIS Data Director  
Welcome and introduction to the workshop, brief overview of rare diseases and the challenges faced

12.05-12.15 **Presentation of Asweknow** by Bruno Sarfati, CEO and Founder, Elise de Beauvais, responsible for RDK application  
Exploring key functionalities of rare disease knowledge digital application

12.15-12.25 **Presentation of UTOPIA case study** by Dr. Tudor Groza  
Unlocking Treatment Options Personalised In-Time Access – a solution for throughout the diagnostic odyssey and beyond that can be deployed in high and low and middle income

12.25-12.35 **Presentation of Mina** by William Declerck, M.D.  
Diving into possibilities of a Q&A chatbot use in clinical settings

12.35-12.45 **Commentary** by Prof. Lizbeth Goodman, Director, SMARTlab/UCD and Huw Williams CTO/Co-director SMARTlab  
SmartLabs representatives provide a commentary on the presented tools

12.45-12.55 **Commentary** by Irina Kubinschi, MedTech Europe, Manager of Government Affairs & Public Policy  
Medical devices industry representative comments on the regulatory landscape for digital solutions for rare diseases

12.55-13.05	<b>Patient perspective</b> by Daniel Lewi, The Cure & Action for Tay-Sachs (CATS) Foundation Patient representative shares their perspectives on the importance and challenges linked with the use of digital solutions in managing rare diseases
13.05-13.15	<b>Closing remarks</b> by Jelena Malinina, EURORDIS Data Director