

# The ALSFRS-R in clinical trials and clinical practice

Thursday 8 December, 2022

14:00–14:45 (Greenwich Mean Time)

Virtual session



In conversation

**Danielle Boyce** and  
**Ruben van Eijk**



**Danielle Boyce, MPH, DPA**

Center for Data Science in Emergency Medicine,  
Department of Emergency Medicine, Johns Hopkins  
University School of Medicine, Baltimore, MD, USA



**Ruben van Eijk, MD, PhD**

University Medical Center (UMC)  
Utrecht, Netherlands

Danielle Boyce is a rare disease advocate, researcher, public speaker, and writer. She holds a master's degree in public health, with an emphasis on epidemiology, and a doctorate in public administration. She has served on several patient and caregiver advisory panels for academic institutions, pharmaceutical companies, not-for-profit organizations, the US Food and Drug Administration (FDA), the American Academy of Pediatrics, and the Patient-Centered Outcomes Research Institute (PCORI). Her children's book, "Charlie's Teacher", is used in children's hospitals throughout the USA.

Ruben van Eijk is a medical doctor and biostatistician. Since 2015 he has been working as a clinical research physician at the Netherlands amyotrophic lateral sclerosis (ALS) centre in Utrecht, the Netherlands. His PhD was entitled "Optimizing the design and conduct of clinical trials for ALS" and his current research focusses on addressing methodological challenges in clinical drug development to further accelerate clinical trials for neuromuscular diseases. He is now working on new statistical models to combine survival and longitudinal data on ALS, as well as developing new endpoints that address the multidimensional nature of ALS and differences in patient preference.

## About the Artist

**Sarah Ezekiel** is one of the world's leading eyegaze artists; she has exhibited all over the UK, including the Royal Academy Schools in London, and at the Katara Art Centre in Doha.

*"Teardrops was created after I fell out of bed one morning. My carer couldn't hear me calling for help and I was lying on the floor for an hour. Feeling bruised and sore, I started to paint and decided that I could create something good from a bad experience. The colours represent my optimism despite having MND."*



Sarah studied art and history of art, but when, at the age of 34, she was diagnosed with motor neuron disease (MND), she believed that she would never create anything again. In fact, she continues to work using assistive devices, offering inspiration, support and a positive outlook to families in a similar situation.