

# Kayentis

Dedicated to eCOA and patient engagement

## Partnering with patients to boost clinical research in rare diseases

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Although much progress has been made in developing scientific knowledge and conducting clinical research in rare diseases, serious challenges remain.

This article examines three key hurdles that are significantly affecting clinical research in rare diseases. It draws upon qualitative research that indicates partnering with patients and ensuring that their voices are heard are among the first and foremost steps to improve the success rate of clinical trials in rare diseases.

Strengthening knowledge-based networks to enable more shared data around the globe, together with a greater digitization in the communication of and rollout of clinical trials are critical steps industry stakeholders should aim to adopt to help offset the hurdles characterized by clinical research in rare diseases: limited knowledge of the pathology, small patient populations that show high variability in the expression of their diseases, plus the significant burden that participating in clinical trials causes to these patients.

By taking these critical steps, clinical trials actors will improve access to and facilitate the running of clinical trials for the ones who need them most.

[Read the full article in Pharma Times:](#)



### Learn more:

- [Overcoming the Complexities of Pediatric Clinical Trials](#)
- [eCOA challenges of long term studies #whitepaper](#)
- [How can digital innovation turn clinical trials into a positive patient and site experience?](#)

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