# A Global Longitudinal Study of PK Deficiency

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# Building on Our Understanding of Pyruvate Kinase Deficiency

Presenting two Peak Registry sub-studies that focus on the patient experience

### Patient-Reported Outcomes sub-study (NCT04964323)

- Aims to characterize patient-reported health-related quality of life and disease burden in patients with PK deficiency, including impact on work productivity and activity impairment
- Open to all adult Peak participants in Italy, the Netherlands, Spain, UK, and US
- Participants will complete self-reported assessments on their desktop PC, laptop, tablet, or mobile phone
- Assessments are collected every 3 months for 24 months

#### Cognition sub-study (NCT04995315)

- Aims to objectively evaluate if PK deficiency has an impact on cognitive performance
- Open to all adult Peak participants in Italy, the Netherlands, and US
- Participants will complete a battery of self-administered cognitive assessments of psychomotor speed, attention, visual learning, and working memory on a laptop or desktop PC
- Assessments are collected at enrollment and again after 90 days

## The Peak Registry and sub-studies provide a unique and impactful opportunity to expand our combined knowledge and understanding of PK deficiency to better support this patient population

Participation in the Peak Registry and sub-studies benefits the community of patients and practitioners seeking information about disease burden, treatment outcomes, and clinical practices. Benefits may include:

- Expanded knowledge of the impact of PK deficiency on patient health-related quality of life and cognition
  - Further engagement of patients via the Patient Community Portal
    - The ability to view graphics of aggregated Peak data, as well as access to a PK deficiency resource library
      - Collaboration with practitioners around the globe who are dedicated to their patients with PK deficiency
        - The opportunity to contribute to the medical discourse around PK deficiency

To learn more, or to participate in the Peak Registry, please visit PeakRegistry.com or email medinfo@agios.com

