

Development of Health-related Quality of Life Instrument for Patients With Cystinosis

NCT05959668

Status	RECRUITING
Sponsor	Cystinose Stiftung
Enrollment	300 participants

Key Eligibility Criteria

Inclusion (4)

- Children, adolescents, and young adults aged 8-26 years (and at least one of their parents) and further parents only of children aged 0-7
- patients have a confirmed diagnosis of cystinosis
- patients have a sufficient knowledge of the German/ English/ French or Spanish language to participate in focus interviews and complete questionnaires
- the informed consent of legal guardian and assent from the patient (if older than eight years) was given

Exclusion (2)

- severe cognitive impairment
- other severe illnesses that strongly determine everyday life

Locations (1 total)

University Medical Center Hamburg-Eppendorf | Center for Psychosocial Medicine | Department of Medical Psychology, Hamburg, Germany