Cohort name (acronym)	NF1 (Neurofibromatosis type 1)
Main focus areas	Health and psychosocial consequences of living with NF1
Source of identification of study population	National Patient Registry and a clinical database of rare diseases
Study population	2,420 individuals from Denmark who have been hospitalized with NF1
	636 individuals identified in the clinical database
	In total, 2,515 individuals with NF1
Design and data collection	
Study design	Cohort study
Setting	Population-based
Data sources (yes/no)	
Registers	Yes
Medical records	No
Questionnaires	Yes
Interviews	No
Physical examinations	No
Bio samples (if yes, specify)	No
Other tests	Neuropsychological assessments
Website and/or contact person	Jeanette Falck Winther, jeanette@cancer.dk