

Elementchapter	elements	value
Common Data elements		
Pseudonym	Pseudonym	string
Personal information	Date of inclusion	date
	Date of birth	date
	Sex	string
Patient status	Patient's status	string
	Date of death	date
Care pathway	First contact with specialised centre	date
Disease history	Moment of onset	string
	Date of onset	date
	Moment of diagnosis	String
	Date of diagnosis	date
Diagnosis	Diagnosis of the rare disease	Orphanet Code
	Genetic diagnosis	HGNC gene code
	Undiagnosed case	HPO code
Biological sample	If yes	yes/no
Link to a biobank	If yes	yes/no
	Biobank	string