

Core Fields in GloBE-Reg Registry	Fields within the NS Module in the GloBE-Reg Registry (MDS fields in bold)				
	Diagnosis	Therapy	Clinician-Reported Outcomes	Adverse Events	Patient/Parent-Reported Outcomes
Consent*	Birth and Parental Details	Growth Hormone (rhGH)	Anthropometry and Pubertal Status	Since the last recorded clinical encounter in the GloBE-Reg Registry, has the patient experienced any untoward medical occurrence (sign, symptom or disease)?	<i>To be developed</i>
Patient Registry ID*	Gestational age	Date of start of first rhGH therapy	Height (cm)		
Centre*	Delivery mode	Date of Start of current rhGH therapy	Weight (kg)		
Clinician Responsible for case*	Birth weight (grams)	Total weekly dose (mg)	BMI		
Date of Birth*	Paternal height (cm)	Reported missed doses in an average month (LA-GH)	Genitalia (Tanner stage)	Since the last recorded clinical encounter in the GloBE-Reg Registry, has the patient experienced any medication error related to the drug?	
Patient Follow-up Status	Maternal height (cm)	Reported missed doses in an average week (Daily-GH)	Right Testicular volume (ml)		
Date of Death*	Mid-parental Height	Therapy stopped	Left Testicular volume (ml)		
Primary Cause of Death*	Participation in Clinical Trials	Other Medications	Breast (Tanner stage)		
Sex at Birth*	Participation in Clinical Trials	Thyroid hormone	Pubic hair (Tanner stage)		
Current Gender*	Past Medical History	Oestrogen	Menarche attained		
Country of Birth	Cardiac surgery	Testosterone	Bone age		
Country of Usual Residence	Feeding difficulties		Cardiovascular Assessment		
Data Shared for Research Purposes	Neoplasia or cranial tumour		Systolic BP (mmHg)		
Can be contacted for collecting PRO	Other comorbidities / surgery		Diastolic BP (mmHg)		
Consent for Newsletters	Genetics		ECG		
Participation in Other Registries	Noonan-Suggestive Clinical Features		Echocardiography		
Name of Registries	Noonan-Associated Genes		Laboratory Assessment		
Registries Patient ID(s)	Comorbidities		Biochemistry		
Biobank Details	Noonan-Associated Comorbidities		IGF-1		
Biobank sample available for Research	Biochemistry at diagnosis		TSH		
Biobank Details	IGF-1		Free T4		
Biobank Patient ID	TSH		HbA1c		
Drug Group*	Free T4		Lipid Profile		
Drug Sub-Group*	HbA1c		Triglyceride		
Drug*	LH		LDL		
Drug indication*	FSH		HDL		
Primary Condition*	Oestradiol		Total cholesterol		
Specific Diagnosis*	Testosterone		Haematology		
Patient Email	Triglyceride		Full Blood Count		
Patient Preferred Language	LDL		Coagulation screen		
*Mandatory core fields	HDL				
	Total cholesterol				
	Imaging at diagnosis				
	Bone age at diagnosis				
	MRI Head/Pituitary				