

Online resource 2

Domain	Variable name	Updated version
Anthropometry		
	Height (cm)	
	Height, SDS	
	Weight (kg)	
	Weight, SDS	
	BMI kg/m ²	
	BMI, SDS	
Basic disease module		
	How was diagnosis reached?	
	Disease components	
	Treatment history	
	Other surgeries	
	Current therapy	
	Disease related hospital admissions since last visit	
	Pregnancy	
	Number of deliveries	
	Is patient alive?	
	Cause of death if applicable	
Disease characteristics		
<i>Musculoskeletal</i>		
	Fractures due to fibrous dysplasia	
	Limb deformity due to fibrous dysplasia	
	Scoliosis due to fibrous dysplasia	
	Pain at fibrous dysplasia site	
<i>Endocrinopathies</i>		
	McCune/Albright related endocrinopathy	
<i>Bone and mineral metabolism</i>		
	Alkaline phosphatase	
	CTX-I	
	Hypophosphatemia, serum confirmation	
	PINP	
	Hypophosphatemia, TmP/GFR confirmation	
	TmP/GFR value	
	Intact FGF-23 value (pg/ml)	
	C-terminal FGF-23 value (U/ml)	
	PTH	
<i>Neoplasms</i>		
	Neoplasms	
	Other neoplasm	

McCune-Albright syndrome	
	Type of endocrinopathy Age at presentation of neonatal hypercortisolism if applicable Age at presentation of precocious puberty if applicable Age at presentation of hyperthyroidism if applicable Age at presentation of growth hormone excess if applicable Age at presentation of hyperprolactinemia if applicable
Craniofacial FD	
	Side of craniofacial lesion
<i>Visual</i>	Best corrected Visual Acuity Was OCT (optical coherence tomography) performed? Visual field left status Visual field right status Nerve palsy left If yes, specify nerve ✓ Nerve palsy right If yes, specify nerve ✓ New visual complaints Underlying eye disease ✓
<i>Ear, nose and throat</i>	ENT complaints Hearing loss type right Hearing loss severity right Hearing loss type left Hearing loss severity left Paranasal sinus involvement left Paranasal sinus involvement right
Therapy	
<i>Past Therapy</i>	FD related medication Indication for FD related medication Endocrinopathy related medication Endocrinopathy related, other therapies
<i>Current therapy</i>	FD related medication Indication for FD related medication Endocrinopathy related medication
<i>Adverse events (current or past therapy related)</i>	Has the patient developed FD related medication adverse events? Please indicate the medication Adverse event

IPMN		
<i>Imaging</i>		
	Imaging technique	
	Cyst diameter	
	Is the cyst located in the head of the pancreas?	
	Is there an enhancing solid component within the cyst?	
	Presence of thickened/enhancing cyst walls?	
	Presence of non-enhancing mural nodule?	
<i>Clinical findings</i>		
	Symptoms related to IPMNs	
<i>Laboratory values</i>		
	CA 19-9 U/ml	
<i>Complications</i>		
	IPMN related complications	
<i>Treatment</i>		
	IPMN treatment	
Fibrous dysplasia with myxoma		
<i>Diagnosis</i>		
	How was the myxoma diagnosed?	
	If it differs from what specified in the Core Data please explain	
<i>Myxoma related clinical findings</i>		
	Number of myxomas	
	Location of myxoma(s)	
	Symptoms	
<i>Myxoma related complications</i>		
	Myxoma related complications	
<i>Myxoma related treatment</i>		
	Myxoma related treatment	
	Were there any surgery related complications?	
	Surgery related complications	
<i>Myxoma cellularity</i>		
	Cellularity based on pathology	
Orthopaedic		
<i>Fractures</i>		
	Fibrous dysplasia related fractures	✓
	Number of fractures	✓
	Year of fracture	✓
	Fracture mechanism	✓
	Fracture location	✓
<i>Surgery</i>		
Patient-reported outcomes		
	How many health professionals do you/the patient see?	

	Which health professionals do you/the patient see regularly?
Patient-reported outcome measures (PROMs)	EQ-5D BPI-SF NPSI
	✓

Online resource 3. Set of clinician and patient-reported variables. Clinician-reported variables were categorised in different domains. A basic disease module collecting general information on the condition was followed by domains covering specific areas of the care, disease subtypes, and disease course. ALP: alkaline phosphatase; BMI: body mass index; BPI-SF: brief pain inventory short form; CTX-I: c-terminal telopeptide of type I collagen; FD: fibrous dysplasia; FGF23: fibroblast growth factor 23; GH: growth hormone; IPMN: intrapapillary mucinous neoplasm; NPSI: neuropathic pain symptom inventory; P1NP: type 1 procollagen amino terminal peptides; PTH: parathyroid hormone; SDS: standard deviation score; TmP/GFR: ratio of tubular maximum reabsorption of phosphate to glomerular filtration rate

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