APR Data Dictionary

1) Patient Demographics and Clinical Phenotype Form contains the following data fields:

Section	Specific data fields
Administration details	Date
	Informed consent
Patient details	Name
	APR ID
	Hospital ID
	Universal patient identifier
	NDIS participation
Patient demographics	Date of birth
	Country of birth
	Gender
	Cultural background
	Language
	Religion
	Education level
Patient household information	Number of people in household
	Relationship to patient
	Age
Patient contact information & patient contacts	Mobile
	Email
	Address
Patient medical history	Allergies
	Medical conditions
Family medical history	Medical conditions
Diagnosis	Date of diagnosis
	Date of onset
	Diagnosis status

	Diagnosis
Current medication(s)	Medications at point of referral
Immunisation history	Vaccinations
	Date
	Doses
Surgery	Surgical procedure
	Date
Chemotherapy	Chemotherapy
	Status
	Date
Patient birth details	Weight
	Length
	Head circumference
	Mother's age (at time of patient's birth)
	Gestational age
	Mode of delivery
	Birth complications
Father's information & mother's	Country of birth
information	Marital status
	Weight
	Height
	Age of puberty/menarche/breast development
Treating doctors information	Attending doctor's name
	Referring doctor's name and specialty

2) Patient Encounter Form contains the following data fields:

Section	Specific data fields
Administration details	Date
	Data inputter's medical/health profession and name

	Patient's APR status (ongoing or withdraw)
Encounter information	Select relevant options (e.g. growth chart, vital signs, clinical notes, treatment(s), adverse event(s), family history, social history)
Growth chart	Patient's age
	Height
	Weight
	BMI
	Span
	Sitting height
	Right arm & left arm
	Right leg & left leg
	Waist circumference
	Hip circumference
	Pubic hair stage
	Tanner puberty scale (male/female)
Vital signs	Temperature
	Respiratory rate
	Heart rate
	Pulse rate
	Systolic blood pressure
	Diastolic blood pressure
Clinical notes	Acute and chronic pain
	Bone age
	Chemotherapy
	Developmental screening
	Nursing
	Nutrition and dietetics
	Occupational therapy
	Post-Anaesthesia Care Unit notes

	Physiotherapy – functional measures (includes 6 minute walk test, time up and go)
	Rheumatology service
	Speech pathology
	Surgery
	Quality of life
Treatments	Growth hormones
	Medications
Adverse Events	Event
	Date occurred
	Relationship with treatment
Family history	Medical conditions of biological parents, siblings and other family members
	Notes
Social history	Days off work/school
	Hospital admissions
	Carer requirements
	Notes