RACP
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3 August 2018

SNOMED CT Submissions Team
Ministry of Health
PO Box 5013
WELLINGTON 6140

By email: Standards@health.govt.nz

To Whom it may concern

Invitation for Feedback on SNOMED CT Subset Development for National Patient Flow: general paediatrics and child developmental services

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to submit feedback on the Ministry of Health's draft SNOMED-CT subsets for General Paediatrics and Child Development.

The RACP works across more than 40 medical specialties to educate, innovate and advocate for excellence in health and medical care. Working with our senior members, the RACP trains the next generation of specialists, while playing a lead role in developing world best practice models of care. We also draw on the skills of our members, to develop policies that promote a healthier society. By working together, our members advance the interest of our profession, our patients and the broader community.

The RACP strongly supports the Ministry of Health providing a clear directive as to the need for national consistency in the implementation of the SNOMED-CT subsets. If District Health Boards are left to contract and arrange their own solutions, there is a risk for inconsistency, information gaps and incompatible data. Implementation must be set in a continuous quality improvement framework, to ensure that learning is captured and contributes to further refinement of the system. **Attached** are two excel spreadsheets and a public comment template with our feedback.

The RACP thanks the Ministry of Health for the opportunity to provide feedback on this consultation, and looks forward to the final version of the subsets. To discuss this submission further, please contact the NZ Policy and Advocacy Unit at policy@racp.org.nz.

Yours sincerely

Jeff Brown

Dr Jeff Brown
New Zealand President
The Royal Australasian College of Physicians

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HISO 10055
SNOMED CT Subsets for General Paediatrics and Child Developmental Services

Draft sets of clinical terms for public comment
released 15 June 2018

Closing date for submissions 3 August 2018

Draft SNOMED subsets of clinical terms for general paediatrics and child developmental services

Public comment on these draft SNOMED subsets of clinical terms for general paediatrics and child developmental services is open until 5pm, Friday, 3 August 2018.

Comments are invited on the content of the spreadsheets. You may comment on the spreadsheet(s) as a whole or any part of the document.

Please use this public comment template to record any *general comments* on the subsets. To record your *comments against clinical terms* within a subset, please download the Draft General Paediatrics Subset or the Draft Child Developmental Subset and enter your feedback within the comments field provided in the worksheet. Additional clinical terms to be considered, should be recorded in the box provided at the end of the worksheet, along with a brief reason.

In your submission, clearly identity yourself and the organisation (if any) that you are representing.

Submissions should be emailed to standards@health.govt.nz by the **3 August 2018**.

A working group will consider all submissions and agree on any changes to the subset before it is published.

Note that the present draft is released for public comment only and is not a published document.

Feedback provided on:	
Draft General Paediatrics Subset	**Yes**
Draft Child Developmental Subset	**Yes**

General Comment
The two subsets (one for general paedatrics, and the other for child development) have a number of commonalities, including for example, references on both subsets to enuresis and failure to thrive. The RACP notes that given the corresponding content and subject matter of each subset, it would be best practice to ensure the subsets are used together rather than individually to code presentations, and ensure the information entered accurately describes the symptoms within a biopsychosocial model of health. Primary and secondary codes would allow for the complexity of cases and presentations to be described. The RACP strongly supports the Ministry of Health providing a clear directive as to the need for national consistency in the implementation of the SNOMED-CT subsets. If District Health Boards are left to contract and arrange their own solutions, there is a risk for inconsistency, information gaps and incompatible data. Implementation must be set in a continuous quality improvement framework, to ensure that learning is captured and contributes to further refinement of the system.

Submitted by:
Name: Dr Jeff Brown, NZ President Organisation: The Royal Australasian College of Physicians

General Paediatrics (Draft)

Public comment submitted by:	
Name:	NZ Policy and Advocacy Unit
Title:	
Organisation:	The Royal Australasian College of Physicians

Number of Clinical Terms: 373

	Clinical Working Group Agreed Term	Concept ID	Additional Notes	Space for feedback / questions *(Note: the text will continue to wrap in this column)*
	Factors Influencing Health Status and Contact with Health Services			
1	Emotional abuse	371773006		
2	Physical child abuse	371779005		
3	Palliative care	103735009		
4	Sexual abuse of child	95922009		
5	Patient referral for socioeconomic factors	41920009		
6	Child into care medical examination	185045002	*To be used for Gateway assessment until NZ specific term created*	
7	Child neglect	418496002		
8	Child abandonment	242037000		
9	Suspected victim of child abuse	162596006		
10	Suspected victim of child neglect	702953007		
11	Living in poverty	11403006		
12	Cultural deprivation	72781007		
13	Housing problem	105531004		
14	Damp housing	398081001		
15	Homeless	32911000		
16	Exposed to tobacco smoke	43381005		
17	Exposure to methamphetamine	711455000	*Use this term for exposure to Methanphetamine until new term is created in SNOMED CT*	
18	Foetal exposure to drug or Fetal exposure to drug	711456004		
19	Foetal exposure to alcohol or Fetal exposure to alcohol	709462001		
	Miscellaneous terms for factors influencing contact with health services			

20	Caregiver emotional health	405191007		
21	Caregiver physical health	405192000		
22	Interpreter needed	315594003		
23	Child in residential care	228122001	*For use in care under mental health, youth justice, child protection, physical disability, intillectual disability, long-term placement*	
24	Refugee family	413323004		
25	Refugee			
26	International adoption			
	Congenital Malformations, Deformations, and Chromosomal Abnormalities			
27	Atrioventricular septal defect OR AVSD - Atrioventricular septal defect	253414002		
28	22q11 partial monosomy syndrome OR Chromosome 22q11 deletion syndrome	449818005		
29	Congenital chromosomal disease OR Chromosomal Syndrome	74345006		
30	Cleft of hard palate	448915004		
31	Cleft of soft palate	253997002		
32	Congenital chordee	64320007		
33	Congenital vesicoureterorenal reflux OR Congenital vesico-uretero-renal reflux	373637000		
34	Down syndrome	41040004		
35	Fragile X chromosome	205720009		
36	Hypospadias, penile	204888000		
37	Hypospadias, penoscrotal	204889008		
38	Hypospadias, perineal	204890004		
39	Hypospadias, balanic	204891000		
40	Hypospadias	416010008		
41	Microcephaly	1829003		
42	Muscular ventricular septal defect	94706008		
43	ASD - Atrial septal defect	70142008		
44	Cleft palate	87979003		
45	VSD - Ventricular septal defect	30288003		

46	Patent ductus arteriosus	83330001		
47	Patent foramen ovale	204317008		
48	Perimembranous ventricular septal defect	109428005		
49	Sinus venosus defect	95268002		
50	Spina bifida occulta	76916001		
51	Ankyloglossia or Tongue-tie	67787004		
52	Trisomy 21- meiotic nondisjunction	205615000		
53	Trisomy 21- mitotic nondisjunction mosaicism Mosaic Down syndrome Mosaic Down's syndrome	205616004		
54	Partial trisomy 21 in Down's syndrome Trisomy 21 - translocation	254264002		
55	Undescended testicle UDT - Undescended testes	204878001		
56	Spina bifida	67531005		
	Injury, Poisoning and Certain Other Consequences of External Causes			
57	Traumatic brain injury	127295002		
58	Non-accidental traumatic head injury to child	700506009		
59	Chemical burn	426284001	*Use for caustic burn*	
60	Thermal burn	314534006		
61	Burn	125666000		
62	Pressure sore Pressure ulcer	399912005		
63	Postmortem care	133904006		
64	Accidental injury	242056005		
65	Non-fatal submersion	87970004		
66	Immunoglobulin E-mediated allergic disorder	422076005		
67	Non-Immunoglobulin E-mediated allergic disorder	422339003		
68	Child abuse	397940009		Child abuse is a generic term and the NZ Paediatrics and Child Healrh Division Committee (NZ PCHDC) considered it could be interpreted too broadly. More definitive terms could be applied to describe the presentation, including inflicted injury or non-accidental injury; which would imply child abuse.
69	Latex allergy	300916003		
70	Drug allergy	416098002		
	Certain Infectious and Parasitic Diseases			

71	Wart	57019003		
72	Asymptomatic HIV infection status	91947003		
73	Symptomatic HIV infection	81000119104		
74	Pseudomonas infection	63398001		
75	Tuberculosis infection	56717001		
76	Congenital infection	82353009		
	Neoplasms			
77	Acute lymphoid leukaemia in remission	91856007		
78	Acute lymphoblastic leukaemia Acute lymphoblastic leukaemia, without mention of	91857003	*Use when 'without mention of remission'*	
79	Neuroblastoma	432328008		
80	Medulloblastoma	443333004		
81	Brain tumor	254935002		
82	Tumor of liver	126851005		
83	Tumor of kidney	126880001		
	Diseases of Blood and Blood-Forming Organs			
84	Anaemia	271737000		
85	Lymphadenopathy	30746006		
86	Generalised enlarged lymph nodes	274741002		
87	Hereditary factor IX deficiency disease	41788008		
88	Hereditary factor VIII deficiency disease	28293008		
89	Hereditary factor XI deficiency disease	49762007		
90	Iron deficiency anaemia	87522002		
91	von Willebrand's disease	128105004		
92	Anaemia-chronic disease	191268006		
93	Haemochromatosis	399187006		
94	Anaemia due to blood loss	413532003		
95	Thalassaemia	40108008		
96	Leucopenia	84828003		
97	Hereditary spherocytosis	55995005		
98	Hereditary elliptocytosis	191169008		
99	G6PD deficiency	62403005		
100	Haemolytic anaemia	61261009		

101	Sickle cell anaemia	127040003		
102	Thrombocytopenia	302215000		
103	Idiopathic thrombocytopenia purpura - ITP or ITP-idiopathic thrombocytopenic purpura	32273002		
104	HUS - Haemolytic uraemic syndrome	111407006		
105	Coagulation disorder	64779008		
106	Easy bruising	424131007		
107	Menorrhagia	386692008		
108	Purpura and/or petechiae	423306009		
109	Leucocytosis	111583006		
110	Reactive lymphadenopathy	445718006		
111	Lymphadenitis	19471005		
	Endocrine, Nutritional and Metabolic Disease			Premature adrenarche is a common condition and should be added to the Endocrine, Nutritional and Metabolic Disease subset. In premature adrenarche, the secretion of adrenal androgen precursors (dehyroepiandrosterone (DHEA) and its sulfate (DHEA(S)) appears concurrently with clinical signs (such as greasy hair, acne and accelerated stature) at around 8/9 years of age. Premature adrenarche should be recognised as a separate event from gonadarche, and differential causes for androgen excess should be ruled out. Utriainen P, Laakso S, Liimatta J, Jääskeläinen J, Voutilainen R. Premature adrenarche – a common condition with variable presentation. Horm Res Paediatr [Internet] 2015; 83(4):221-31. https://www.ncbi.nlm.nih.gov/pubmed/25676474. Kaplowitz P. Diagnosing children with signs of early puberty: knowing when to test and when to just monitor. Editorial. [Internet] Exp Rev Endocrinol & Metabol 2016; 11(4):297-99. https://www.tandfonline.com/doi/full/10.1080/17446651.2016.1191350.
112	Ambiguous genitalia	21321009		
113	Abnormal weight gain	161833006		
114	Abnormal weight loss	267024001		
115	Tall stature	248328003		
116	Marfan syndrome	19346006		
117	Klinefelter syndrome	22053006		
118	Turner syndrome	38804009		
119	Noonan syndrome	205824006		
120	Williams syndrome	63247009		
121	Alagille syndrome	31742004		

122	Feeding difficulties or Feeding difficulties and mismanagement	274540003		
123	Congenital adrenal hyperplasia	237751000		
124	Disorder of sexual differentiation	39179006		
125	Cystic fibrosis with DIOS			Acronyms such as Distal Intestinal Obstruction Syndrome (DIOS) should be spelled in full to avoid confusion or misunderstanding.
126	Delayed puberty	400003000		
127	Hypopituitarism	74728003		The RACP notes that Hypopituitarism and Panhypopituitarism are very similar; the differentiating factor between the two diagnoses is to do with how many of the pituitary hormones are experiencing reduced secretion.
128	Panhypopituitarism	32390006		
129	Hypothyroidism	40930008		
130	Central hypothyroidism	26692000		
131	Graves disease	237824009		The RACP recommends the Working Group consider hyperthyroidism in place of Graves Disease. While Graves disease is the most common cause of hyperthyroidism (around 80 per cent of people with hyperthyroidism will have Graves disease), there are other causes, such as toxic multinodular goitre and solitary toxic adenoma. De Leo S, Lee SY, Braverman LE. Hyperthyroidism. Lancet [Internet] 2016; 388(10047):906-18. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5014602/. Shulman DI, Muhar I, Jorgensen V, Diamond FB, Bercu BB, Root AW. Autoimmune hyperthyroidism in prepubertal children and adolescents: Comparison of clinical and biochemical features at diagnosis and responses to medical therapy. Thyroid [Internet] 1997; 7(5):755-60. https://www.ncbi.nlm.nih.gov/pubmed/9349579
132	Diabetes mellitus type 1	46635009		
133	Diabetes mellitus type 2	44054006		
134	Diabetes mellitus due to cystic fibrosis	427089005		
135	Precocious puberty	400179000		
136	Type I diabetes mellitus poorly controlled	444073006		The RACP notes that while “poorly controlled” is a common phrase in the literature, in the context of clinical terminology judgmental wording should be kept to a minimum. The RACP suggests that “blood glucose and HBA1c targets not met” could be used in place of “poorly controlled”.
137	Cystic fibrosis	190905008		
138	Type 1 diabetes mellitus without complication	313435000		Members felt that “type 1 diabetes mellitus without complication” required further clarification by the Working Group, as “without complication” was hard to define. Would this term refer to an instance, for example, of a one-off elevated urine microalbumin or mild background retinopathy constitute a complication, or is the Working Group referring to complications from another health condition.
139	Short stature	237836003		
140	Constitutional delay of growth and puberty	237813007		
141	Familial short stature	432526008		
142	G6PD deficiency			

143	Impaired glucose tolerance	9414007		
144	Abnormal human growth hormone	131004002		Further definition is required for this clinical term to clarify if by “abnormal” the Working Group means levels are too high or too low. The RACP notes that best practice for human growth hormone testing requires specialised stimulatory testing, and should not be based on single levels.
145	Rickets	41345002		
146	Storage disease	34420000		
147	Mitochondrial disease	240096000		
148	Osteogenesis imperfecta	78314001		
149	Failure to thrive - child	432788009		“Failure to thrive – child” is not accompanied by Failure to thrive – infant”. It is assumed that the Working Group is using the Ministry of Health’s definitions of child as being aged between 0-14 years (as used in the New Zealand Health Survey). The RACP notes that the Child Development subset includes “Failure to thrive” (54840006) in the Eating Disorders category but does not specify “child”. Ministry of Health. Methodology Report 2016/17. New Zealand Health Survey. Wellington: Ministry of Health; 2017. https://www.health.govt.nz/publication/methodology-report-2016-17-new-zealand-health-survey.
150	Abnormal blood test	151271000119102		
151	MODY - Maturity-onset diabetes of the young	609561005		
	Diseases of the Circulatory System			The RACP recommends that hypertension is added to this category. While the General Paediatrics subset includes pulmonary hypertension (70995007) and benign intercranial hypertension (68267002), a more generic category of hypertension should be included. This is particularly salient with regards to increases in childhood obesity, as hypertension is a relatively common comorbidity with obesity. Rao G. Diagnosis, epidemiology and management of hypertension in children. Paediatrics. [Internet] 2016; 138(2): e20153616. http://pediatrics.aappublications.org/content/138/2/e20153616.long Falkner B. Hypertension in children and adolescents: epidemiology and natural history. Pediatr Nephrol [Internet] 2010; 25(7):1219-24. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2874036/
152	Arrhythmia	698247007		
153	Kawasaki's disease	75053002		
154	Syncope and collapse	309585006		
155	Functional heart murmur	59935001	*Use this SNOMED concept for Innocent heart murmur*	
156	Palpitations	80313002		
157	Atrial fibrillation and flutter	195080001		
158	Rheumatic heart disease	23685000		
159	Non-rheumatic heart valve disorder	274097009		
160	Acute rheumatic fever	26424001		
161	Prolonged QT interval	111975006		
162	SVT - Supraventricular tachycardia	6456007		
163	Heart murmur	88610006		
164	Coarctation of aorta	7305005		
165	ASD - Atrial septal defect			

166	VSD - Ventricular septal defect			
167	Connective tissue disease	105969002		
	Diseases of the Nervous System			The RACP notes that seizure is absent from the draft subset and not listed under 'Epilepsy', or under the more generic category of 'Symptoms'. The RACP recommends seizure is added to the subset category of Symptoms rather than Epilepsy. Although seizures are the recurrent feature of epilepsy, the experience of one seizure does not necessarily result in a diagnosis of epilepsy, and around 10 per cent of the population will experience a seizure at some point in their lifetime. The World Health Organization and the International League Against Epilepsy define epilepsy as at least two unprovoked (or reflex) seizures occurring more than 24 hours apart. International League Against Epilepsy. https://www.ilae.org/guidelines/definition-and-classification/definition-of-epilepsy-2014 World Health Organization. Epilepsy fact sheet. http://www.who.int/en/news-room/fact-sheets/detail/epilepsy The RACP supports the addition of Charcot-Marie-Tooth Disease (CMT), previously known as Hereditary and Sensory Motor Neuropathy. CMT is one of the most prevalent genetic conditions in the paediatric population. Jani-Ascadi A, Ounpuu S, Pierz K, Ascadi G. Paediatric Charcot-Marie-Tooth disease. Paediatr Clin North Am [Internet] 2015; 62(3):767-86. Available from https://www.ncbi.nlm.nih.gov/pubmed/26022174.
	Epilepsy			
168	Epilepsy	84757009		
	Headache			
169	Drug induced headache	294091000119104		
170	Headache	25064002		
171	Cluster headache syndrome	193031009		
172	Migraine	37796009		
173	Chronic headache disorder	431237007		
174	Benign intracranial hypertension	68267002		
	Hydrocephalus			
175	Obstructive hydrocephalus	230746009		
176	Hydrocephalus	230745008		
177	Communicating hydrocephalus	271569006		
	Primary muscle disorders			
178	Muscular dystrophy	73297009		
179	Myopathy	129565002		
180	Fibromyalgia	203082005		
181	Duchenne muscular dystrophy	76670001		
182	Becker muscular dystrophy	387732009		
183	Myotonic dystrophy	77956009		
184	Guillain-Barré syndrome	40956001		
185	Spinal muscular atrophy type I	64383006		
186	Spinal muscular atrophy type II	128212001		

187	Spinal muscular atrophy type III	54280009		
188	Miller-Fisher syndrome	1767005		
189	Facioscapulohumeral muscular dystrophy	399091004		
	Sleep disorders			
189	Central sleep apnoea syndrome	27405005		
190	Obstructive sleep apnoea syndrome	78275009		
191	Sleep disorder	39898005		
192	Behaviour sleep disorder	53888004		
193	Parasomnia	58690002		
194	Night terrors	89675003		
195	Nightmares	419145002		
196	Somnambulism	80495009		
197	Restless leg syndrome	32914008		
198	Difficulty in sleep maintenance	67233009		
199	Delayed onset of sleep	401161007		
	Symptoms			
200	Febrile convulsion	41497008		
201	Chronic fatigue syndrome	52702003		
202	Syncope and collapse			
	Diseases of the Eye and Adnexa			This collection of clinical terms does not include Nystagmus (involuntary rhythmic oscillation of the eyes). In children, the most common form is infantile nystagmus syndrome, and will not typically be present at birth (more likely 2-3 months of age). Nystagmus can be associated with conditions such as Albinism, retinal dystrophies and Down Syndrome. Papageorgiou E, McLean RJ, Gottlob I. Nystagmus in childhood. Paediatr Neonatol [Internet] 2014;55(5):341-51. https://www.ncbi.nlm.nih.gov/pubmed/25086850. Penix K, Swanson MW, DeCarlo DK. Nystagmus in paediatric patients: interventions and patient-focused perspectives. Clin Ophthalmol. [Internet] 2015; 9:1527-1536. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4551307/.
203	Eye examination	36228007		
204	Chalazion	1482004		
205	Juvenile cataract	399336001		
206	Cataract - developmental / non-senile	399305009		
207	Congenital glaucoma	204113001		
208	Congenital nasolacrimal duct obstruction	193994000		
209	Corneal opacity	64634000		
210	Non-accidental injury to child	158094009		Members queried the inclusion of this generic clinical term (which is used to denote harm, abuse and/or neglect of a child) in the category of diseases of the Eye and Adnexa. Members did note, however, that if the Subset Working Group intended to refer to an injury to a child's eye that may have occurred as the result of abuse, that retinal hemorrhage could be more accurate.
211	Retinopathy of prematurity	415297005		
212	Retinoblastoma	370967009		

	Diseases of the Ear and Mastoid Process							
213	Tracheostomy	48387007						
214	Allergic rhinitis	61582004						
215	Acute otitis media	3110003						
216	Chronic suppurative otitis media	38394007						
217	Cholesteatoma	363668000						
218	Mastoiditis	52404001						
219	Eustachian tube dysfunction	56713002						
220	Conductive hearing loss	44057004						
221	Sensorineural hearing loss	60700002						
222	Cochlear implant in situ	449840001						
223	Mixed hearing loss	77507001						
224	Laryngomalacia	38086007						
225	Nasal polyp							
226	Cleft lip	80281008						
227	Dental caries	80967001						
228	Ankyloglossia or Tongue-tie							
229	Adenotonsillar hypertrophy	66622006						
230	Adenoid hypertrophy	111591002						
231	Tonsillar hypertrophy	46689006						
232	Pierre Robin syndrome	4602007						
233	Retrognathia	109515000						
234	Micrognathia	32958008						
235	Macroglossia	25273001						
236	VACTERL syndrome	431395004						
237	CHARGE association	47535005						
238	Subglottic stenosis	22668006						
239	Choanal atresia	204508009						
240	Chronic serous otitis media	81564005						
	Diseases of the respiratory system							
241	Chronic cough	68154008						
242	Chronic lung disease	413839001						
243	Stridor	70407001						

244	Recurrent pneumonia	699014000		
245	Asthma	195967001		
246	Recurrent upper respiratory tract infection	195708003		
247	Recurrent lower respiratory tract infection	448739000		
248	Restrictive lung disease	36485005		
249	Cystic fibrosis			
250	Bronchiolitis obliterans	40100001		
251	Congenital cystic lung	87119009		
252	Congenital lobar emphysema	66987001		
253	Pulmonary sequestration			
254	Pectus carinatum	38774000		
255	Pectus excavatum	391987005		
256	Diaphragmatic hernia	39839004		
257	Wheezing	56018004		
258	Bronchiectasis	12295008		
259	Bronchitis	32398004		
260	Chronic sinusitis	40055000		
	Diseases of the digestive system			Several common digestive system symptoms, such as constipation, soiling, nocturnal and daytime enuresis are listed in the Child Development subset as “other behavioural and emotional disorders” rather than the General Paediatrics subset. Constipation is one of the most common presentations in general paediatrics – constipation will affect between 1 and 30 per cent of children worldwide. Nurko S, Zimmerman LA. Evaluation and treatment of constipation in children and adolescents. Am Fam Physician [Internet] 2014;90(2):82-90. https://www.ncbi.nlm.nih.gov/pubmed/25077577.
261	Vitamin D deficiency	34713006		
262	Bowel problem	309615009		
263	Encopresis	302690004		
264	Abdominal pain	21522001		
265	Infantile colic	35363006		
266	Anal fissure	30037006		
267	Coeliac disease	396331005		
268	IBD - Inflammatory bowel disease	24526004		
269	Pancreatic insufficiency	37992001		
270	Tube feeding	61420007		
271	Hirschsprung's disease	204739008		
272	Omphalocele	18735004		
273	GORD - Gastro-oesophageal reflux disease	235595009		

274	Prune belly syndrome	5187006		
275	Recurrent abdominal pain	439469002		
276	NASH - Nonalcoholic steatohepatitis	442685003		
277	Functional abdominal pain syndrome	449890002		
278	IBS - Irritable bowel syndrome	10743008		
279	Crohn's disease	34000006		
280	Ulcerative colitis	64766004		
281	Short gut syndrome	26629001		
282	Abnormal liver function	75183008		
283	Biliary atresia	77480004		
284	Alagille syndrome			
285	Allergic enterocolitis	197024006		
286	Adverse reaction to food	370540009		
287	Eosinophilic oesophagitis	235599003		
288	Oesophageal atresia	26179002		
289	Tracheoesophageal fistula	95435007		
290	Fistula in ano	72779005		
291	Toddler's diarrhoea	39963006		
292	Gastroschisis	72951007		
293	Chronic diarrhoea	236071009		
294	Asplenia	707147002		The RACP notes that Asplenia (absence of normal spleen function) is incorporated in the draft subset; however an enlarged spleen is a clinical sign associated with a number of diagnoses, including sickle cell disease and lymphoma. Brousse V, Elie C, Benkerrou, M, Odievre MH, Lesprit E et al. Acute splenic sequestration crisis in sickle cell disease: cohort study of 190 paediatric patients. Br J Haematol [Internet] 2012; 156(5):643-48. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2141.2011.08999.x. Cleary AG, McDowell H, Sills JA. Polyarticular juvenile idiopathic arthritis treated with methotrexate complicated by the development of non-Hodgkin's lymphoma. Arch Dis Childhood [Internet] 2002; 86(1). https://adc.bmj.com/content/86/1/47.short.
295	Solid organ transplant	313039003		
296	Hepatitis	128241005		
297	Duodenal atresia	51118003		
298	Anal atresia	204712000		
299	Ileal atresia	25896009		
300	Jejunal atresia	360491009		
301	Cavernous haemangioma	416824008		

302	Hepatic haemangioma	93469006		
	Diseases of the Skin and Subcutaneous Tissue			
303	TS - Tuberous sclerosis	7199000		
304	Eczema	43116000		
305	Rash	271807003		
306	Haemangioma	400210000		
307	Neurocutaneous syndrome	78572006		
308	Neurofibromatosis type 1	92824003		
309	Neurofibromatosis type 2	92503002		
310	Neurofibromatosis type 3	254240003		
311	Recurrent skin infection	736979001		
312	Alopecia	56317004		
	Diseases of the Genitourinary System			Enuresis is included in both Child Development and General Paediatrics subsets; however only the Child Development subset differentiates between diurnal and nocturnal enuresis. The RACP recommends both subsets use the differentiated terms (as in the Child Development subset) across both subsets for consistency.
313	Kidney stone or Renal stone	95570007		
314	Ureteric stone or Ureteric calculus	31054009		
315	Hydrocoele	55434001	*Use this code for Hydrocele - unspecified*	
316	Hydronephrosis with ureteropelvic junction obstruction	310670008		
317	Isolated proteinuria	12491000132101		
318	Hydronephrosis	43064006		
319	VUR - Vesicoureteric reflux	197811007		
320	PUV - Posterior urethral valve	253900005		
321	UTI - Urinary tract infection	68566005		
322	Enuresis			
323	Recurrent UTI - urinary tract infection	197927001		
324	Polycystic kidney disease	82525005		
	Neo-natal			
325	HIE - Preinatal hypoxic - ischaemic encephaloopathy	126945001		
326	Chronic lung disease of prematurity	67569000		
327	Neonatal encephalopathy	95628005		
328	Neonatal Abstinence Syndrome	414819007		

329	ROP - Retinopathy of prematurity	415297005		
330	SGA - small for gestational age	267258002		
331	LGA - large for gestational age	199616008		
332	IUGR - intrauterine growth restriction	22033007		
333	IVH - intraventricular haemorrhage	23276006		
334	Congenital cystic adenomatoid malformation of lung	111318005		
335	Pulmonary sequestration	18620009		
336	PVL perinventricular leucomalacia	230769007		
337	Apnoea of prematurity	276544005		
338	Myelomeningocele	414667000		
339	Cephalohaematoma	83095000		
340	Pulmonary hypertension	70995007		
	Other possible reasons for referral / diagnosis			
341	Follow-up visit	185389009		
342	Growth/development surveillance	410390008		
343	Child in care	160870005		
344	Prematurity <23 weeks	722839000		
345	Baby premature 23 weeks	722840003		
346	Baby premature 24 weeks	15887011000119107		
347	Baby premature 25 weeks	15887051000119108		
348	Baby premature 26 weeks	15887091000119103		
349	Baby premature 27 weeks	15887131000119101		
350	Baby premature 28 weeks	15750001000119103		
351	Baby premature 29 weeks	15750041000119101		
352	Baby premature 30 weeks	15750081000119106		
353	Baby premature 31 weeks	15635451000119107		
354	Baby premature 32 weeks	15635411000119106		
355	Baby premature 33 weeks	15635371000119105		
356	Baby premature 34 weeks	15635331000119107		
357	Baby premature 35 weeks	15635291000119101		
358	Baby premature 36 weeks	310530008		
359	Postmature infancy	16207008		
360	Post-term infant - 42 weeks plus	288270007		
361	Screening for cancer	15886004		
362	Monitoring of patient with cancer	399427004		

363	Jaundice	18165001		
364	Hernia	52515009		
365	Atypical mycobacterial infection	111812000		
366	Vomiting	422400008		Vomiting is included under a generic “other” category. Members support vomiting being included under a “symptoms” category in the Diseases of the Digestive System section, similar to that used in the Diseases of the Nervous System section for convulsions.
367	Myasthenia gravis	91637004		
368	Abnormal immunology finding	309571001		
369	Acquired immunodeficiency syndrome Acquired immunodeficiencies	62479008		This clinical term combines Acquired Immunodeficiency Syndrome (AIDS) and Acquired Immunodeficiency, which are two separate diagnoses, although tend to be used interchangeably among the general public. To avoid confusion, the RACP recommends the Working Group split these terms into two categories.
370	Congenital immunodeficiency disease	36138009		
371	Recurrent bacterial infection	428875002		
372	Hypotonia	398152000		
373	Neurological finding	102957003		
374	Plagiocephaly	21850008		
375	Nephrotic syndrome	52254009		
376	PSGN - Post-streptococcal glomerulonephritis	68544003		

Additional terms for consideration	
Clinical Term	***Reason for suggested inclusion***
Hyperglycaemia	The RACP recommends that Hyperglycaemia, or high blood sugar is added as a clinical term to the General Paediatrics subset. Hyperglycaemia is frequently associated with diabetes mellitus (diagnosed or undiagnosed); and although less common in children, can be induced through stress, acute critical illness such as stroke, or a prolonged surgical intervention. Finlayson C, Zimmerman D. Hyperglycaemia not due to diabetes mellitus. Clin Paediatr Emerg Med. [Internet] 2009; 10(4):252-55. https://www.sciencedirect.com/science/article/pii/S1522840109000949
Hypoglycaemia	Precise definitions, cutoffs and best practice treatment for Hypoglycaemia (low blood sugar) have been the subject of debate, with differences emerging in the blood glucose level at which to treat. There is general consensus that blood glucose of 2.6mM is the cutoff, although there is evidence that some individuals may have different levels of susceptibility. Koh T, Vong SK. Definition of neonatal hypoglycaemia: is there a change? J Paediatr Child Health [Internet] 1996; 32(4):302-05. https://www.ncbi.nlm.nih.gov/pubmed/8844534 Harding JE, Harris DL, Hegarty JE, Alsweiler JM, McKinlay CJD. An emerging evidence base for the management of neonatal hypoglycaemia. Early Hum Dev [Internet] 2017; 104:51-6. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5280577/.
Hyperglycaemia in neonate	Hyperglycaemia is a common issue in babies born at very low birthweight – incidence has been estimated at more than 50 per cent of babies with a birthweight of less than 1000g. Hyperglycaemia is associated with intraventricular haemorrhage and greater risk of mortality. Alsweiler JM, Kuschel CA, Bloomfield FH. Survey of the management of neonatal hyperglycaemia in Australasia. J Paediatr Child Health [Internet] 2007; 43(9)632-35. https://www.ncbi.nlm.nih.gov/pubmed/17608650.

Gender dysphoria – for addition General Paediatrics subset under sexual health	In 2018, the World Health Organization (WHO) reclassified gender dysphoria from a mental health condition to a sexual health condition. The RACP notes that gender dysphoria has a diversity of presentations, including but not limited to transgender – male; transgender – female; and transgender – nonbinary. Each presentation has different management and service requirements, meaning that an umbrella term of "gender dysphoria" will not entail the specific differences which are crucial for service planning. World Health Organization. WHO releases new international classification of diseases ICD-11. Media release 18 June 2018. http://www.who.int/news-room/detail/18-06-2018-who-releases-new-international-classification-of-diseases-(icd-11) RCH Standards of care for transgender children https://www.rch.org.au/uploadedFiles/Main/Content/adolescent-medicine/australian-standards-of-care-and-treatment-guidelines-for-trans-and-gender-diverse-children-and-adolescents.pdf
Sexual health assessment	The RACP notes that the age of transition for adolescents from Paediatric Services to Adult Services can vary according to subspecialty, and the protocols of the service to which they present. The RACP recommends the subsets are flexible and broad enough to cover all potential case presentations to age 18 and encourages the Working Group to include a sexual health assessment as a clinical term.
Central pain sensitisation	The RACP supports central pain sensitisation being added to the clinical terms in the Diseases of the Neurological System category. Members note that many of presentations for chronic pain in the older paediatric population have central pain sensitisation or central pain syndrome, which is more descriptive of pain beyond chronic headaches or abdominal pain, particularly when limbs are the site of pain for these patients.
Contraception	The RACP notes that many paediatricians may identify a need for contraception as part of a clinical assessment for patients in the older paediatric population. This is important information to capture as part of coding practices – particularly when adolescents may have limited or sporadic engagement with health services. The RACP acknowledges that SNOMED-CT may have identified terms for contraception as a "procedure" in the General Paediatrics set or be determined as better positioned in the child development subset, such as "risk for pregnancy".
Sexually Transmitted Infection – under Infectious Diseases in the General Paediatrics subset	The RACP recommends that Sexually Transmitted Infection (STI) is added to the Infectious Diseases category in the General Paediatrics subset. Members noted that STI presentations were not uncommon in the older paediatric population and there is an important public health focus on reducing further STI transmission in the community. Specific codes for STIs (chlamydia, gonorrhea, genital warts) or a reference to a sexual health subset would be useful if there was an intention for wider uptake in the health sector (into primary health organisations and community health providers).
Dysmenorrhea –– for addition to Genitourinary system under the General Paediatrics subset	Dysmenorrhea is the most common gynecological complaint among adolescents and young adults. While the majority will experience primary (functional) Dysmenorrhea associated with menstrual cycles, around 10 per cent will present with secondary Dysmenorrhea, which is associated with pelvic abnormalities, of which endometriosis is the most common cause. Harel Z. Dysmenorrhea in adolescents and young adults: etiology and management. J Paediatr Adolesc Gynaecol [Internet] 2006; 19:363-71. Available from https://www.jpagonline.org/article/S1083-3188(06)00241-5/fulltext.
Tobacco, Alcohol, and other substance abuse	The RACP recommends the Working Group add clinical terms for current and/or ever use of common substances, such as alcohol and tobacco, and a code for any illicit substance use. Although there is evidence that adolescents are using tobacco less (more than 80 per cent of Year 10s reported never smoking), around 61 per cent of young people aged 12-24 are estimated to have used alcohol ever. The use of these products and substances is an important risk factor and is significant due to the health implications and disease risks from long-term use. There are also significant inequalities in daily tobacco use among Year 10 students, with Māori and Pasifika students reporting higher rates of daily smoking (5.3 and 3.5 per cent respectively, compared with 0.9 per cent for non-Māori, non-Pasifika students). Health Promotion Agency. Alcohol and young people: a review of New Zealand and other international literature. Wellington: Health Promotion Agency; 2017. Available from https://www.hpa.org.nz/research-library/research-publications/alcohol-and-young-people-a-review-of-new-zealand-and-other-international-literature. ASH Action for Smokefree 2025. Topline results 2017 ASH Year 10 snapshot. Available from https://www.ash.org.nz/ash_year_10.

Child Developmental Services (Draft)

Public comment submitted by:	
Name:	NZ Policy and Advocacy Unit
Title:	
Organisation:	The Royal Australasian College of Physicians

Number of Clinical Terms: 115

	Clinical Working Group Agreed Term	Concept ID	Additional notes specific to spreadsheet	Space for feedback / questions *(Note: the text will continue to wrap in this column)*
1	Mental and Behavioural Disorders			
2	*Conduct disorders*			
3	Behavioural concern	277843001		
4	Challenging behaviour	248041005		
5	Conduct disorder	430909002		
6	Oppositional defiant disorder	18941000		
7	Aggression	61372001		
8	*Developmental delays*			
9	Speech, language, communication difficulty	284530008		
10	Speech, language, communication disorder	231543005		
11	Stammering or Stuttering	39423001		
12	Disorder of Voice disorder or Voice disorder	47004009		
13	Expressive language delay	229734008		
14	Receptive language delay	229736005		
15	Mixed receptive-expressive language disorder	25766007		
16	Articulation disorder	386701004		

17	Developmental delay in receptive-expressive language	702528003		
18	Gross motor development delay	430099007		
19	Multiple Developmental difficulties		*SNOMED concept to be identified*	
20	Development delay in social skills	703478008		
21	Developmental coordination disorder	27544004		
22	Global developmental delay	224958001		
23	Developmental delay in fine motor function	703477003		
24	Developmental delay, feeding	426881004		
25	Tic disorder	568005		
26	Tourette syndrome	5158005		
27	*Developmental disorders of scholastic skills*			
28	Learning difficulties	161129001		
29	Specific learning disorder		*SNOMED concept to be identified*	
30	*Developmental disorders - mixed*			
31	Chromosomal anomaly	409709004		
32	Foetal valproate syndrome or Fetal valproate syndrome	17231009		
33	Foetal hydantoin syndrome or Fetal hydantoin syndrome	70065001		
34	Foetal Alcohol Spectrum Disorder or Fetal Alcohol Spectrum Disorder	609437000		
35	Medication review	182836005		
36	*Eating Disorders*			
37	Failure to thrive	54840006		

38	Weight loss	89362005		
39	Feeding concern	78164000		
40	Failure to gain weight	36440009		
41	Anorexia nervosa	56882008		
42	Bulimia nervosa	78004001		
43	Eating disorder	72366004		
44	Healthy child	102506008		
45	Development within normal limits	9908006		
46	Normal growth or Growth within normal limits	58236001		
47	Normal behaviour or Behaviour within normal limits	51746009		
48	Pica	14077003		
49	Parenteral feeding	25156005		
50	Enteral feeding	229912004		
51	*Raising Healthy Kids*			
52	Obesity	414916001		
53	Morbid obesity	238136002		
54	Overweight	238131007		
55	*Hyperkinetic disorders*			
56	Inattention	22058002		
57	Hyperactivity	44548000		
58	Impulsivity	39178003		
59	ADHD - ADD - Attention deficit hyperactivity disorder	406506008	*Also use this term for ADD disorders.*	

60	*Mood (affective) disorders*			
61	Anxiety	48694002		
62	Mood disorder	46206005		
63	Panic attack	225624000		
64	Self-harm or Self-injurious behaviour	248062006		
65	School refusal	248052004		
66	PTSD - Post-traumatic stress disorder	47505003		
67	Anxiety disorder	197480006		
68	Depression	35489007		
69	Obsessive compulsive disorder	191736004		
70	Selective mutism	71959007		
71	Suicidal ideation	6471006		
72	Gender dysphoria	93461009		
73	Adjustment disorder	17226007		
74	*Other behavioural and emotional disorders*			
75	Soiling	276484003		
76	Constipation	14760008		
77	Encopresis	302690004		
78	Nocturnal enuresis	8009008		
79	Daytime enuresis or Daytime wetting	281862002		
80	*Pervasive developmental disorders*			
81	Sensory issues	162246009		
82	Suspected autism	401204006		
83	Sensory processing disorder	425988004		

84	Mild intellectual disability			
85	Moderate intellectual disability			
86	Severe intellectual disability			
87	ASD - Autism	408856003	*Requires a qualifier value to be assigned for the appropriate level of the diagnosis*	
88	*Genetic disorders*			
89	Retts syndrome	68618008		
90	*Symptoms*			
91	Pain	22253000	*To be used for unspecified pain*	
92	Chronic pain	82423001		
93	Acute pain	274663001		
94	*Assessments*			
95	Standardised development assessment	31958005		
96	Surveillance of condition	225418004		
97	WISC Assessment	15218003		
98	Bayley's Assessment	715911009		
99	WPPSI - Wechsler pre-school and primary scale of intelligence	273922002		
100	Griffith Assessment	281692008		
101	Housing assessment	225340009		
102	*Others*			

103	Substance abuse	66214007		The RACP recommends the Working Group add clinical terms for current and/or ever use of common substances, such as alcohol and tobacco, and a code for any illicit substance use. Although there is evidence that adolescents are using tobacco less (more than 80 per cent of Year 10s reported never smoking), around 61 per cent of young people aged 12-24 are estimated to have used alcohol ever. The use of these products and substances is an important risk factor and is significant due to the health implications and disease risks from long-term use. There are also significant inequalities in daily tobacco use among Year 10 students, with Māori and Pasifika students reporting higher rates of daily smoking (5.3 and 3.5 per cent respectively, compared with 0.9 per cent for non-Māori, non-Pasifika students). Health Promotion Agency. Alcohol and young people: a review of New Zealand and other international literature. Wellington: Health Promotion Agency; 2017. Available from https://www.hpa.org.nz/research-library/research-publications/alcohol-and-young-people-a-review-of-new-zealand-and-other-international-literature. ASH Action for Smokefree 2025. Topline results 2017 ASH Year 10 snapshot. Available from https://www.ash.org.nz/ash_year_10.
104	Gait abnormality	22325002		
105	Equipment-related management procedure	363108004		
106	Developmental regression	609225004		
107	Diseases of the Nervous System			The RACP notes that seizure is absent from the draft subset and not listed under 'Epilepsy', or under the more generic category of 'Symptoms'. The RACP recommends seizure is added to the subset category of Symptoms rather than Epilepsy. Although seizures are the recurrent feature of epilepsy, the experience of one seizure does not necessarily result in a diagnosis of epilepsy, and around 10 per cent of the population will experience a seizure at some point in their lifetime. The World Health Organization and the International League Against Epilepsy define epilepsy as at least two unprovoked (or reflex) seizures occurring more than 24 hours apart. International League Against Epilepsy. https://www.ilae.org/guidelines/definition-and-classification/definition-of-epilepsy-2014 World Health Organization. Epilepsy fact sheet. http://www.who.int/en/news-room/fact-sheets/detail/epilepsy The RACP supports the addition of Charcot-Marie-Tooth Disease (CMT), previously known as Hereditary and Sensory Motor Neuropathy. CMT is one of the most prevalent genetic conditions in the paediatric population. Jani-Ascadi A, Ounpuu S, Pierz K, Ascadi G. Paediatric Charcot-Marie-Tooth disease. Paediatr Clin North Am [Internet] 2015; 62(3):767-86. Available from https://www.ncbi.nlm.nih.gov/pubmed/26022174.

108	Cerebral palsy	128188000	*Additional information (eg level), should be recorded in the Cerebral palsy register.*	
109	Diseases of the Eye and Adnexa			This collection of clinical terms does not include Nystagmus (involuntary rhythmic oscillation of the eyes). In children, the most common form is infantile nystagmus syndrome, and will not typically be present at birth (more likely 2-3 months of age). Nystagmus can be associated with conditions such as Albinism, retinal dystrophies and Down Syndrome. Papageorgiou E, McLean RJ, Gottlob I. Nystagmus in childhood. Paediatr Neonatol [Internet] 2014;55(5):341-51. https://www.ncbi.nlm.nih.gov/pubmed/25086850. Penix K, Swanson MW, DeCarlo DK. Nystagmus in paediatric patients: interventions and patient-focused perspectives. Clin Ophthalmol. [Internet] 2015; 9:1527-1536. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4551307/.
110	Eye examination	36228007		
111	Chalazion	1482004		
112	Juvenile cataract	399336001		
113	Cataract - developmental / non-senile	399305009		
114	Congenital glaucoma	204113001		
115	Congenital nasolacrimal duct obstruction	193994000		
116	Corneal opacity	64634000		
117	Non-accidental injury to child	158094009		
118	Retinopathy of prematurity	415297005		
119	Retinoblastoma	370967009		
120	Diseases of the Ear and Mastoid Process			
121	Hearing impairment	15188001		
122	Diseases of the Musculoskeletal System & Connective Tissue			
123	Neuromuscular disorder	257277002		
124	Imaging of brain abnormal	442731005		

125	Orthopaedics			
126	Torticollis	70070008		
127	Joint hypermobility	298181000		
128	Talipes equinovarus	397932003		
129	Lower extremity deformity	449715001		
130	Arthrogryposis	111246005		
131	Developmental dysplasia of the hip	52781008		
132	Toe walking	250018006		
133	Craniosynostosis	57219006		
134	Gait abnormality			
135	Erb's palsy	78141002		
136	Scoliosis	298382003		
137	Hemihypertrophy		*SNOMED concept to be identified*	
138	Miscellaneous			
139	No diagnostic abnormality	23875004		
140	Diagnosis not made	723663001		
141	Rheumatological condition		*Refer to Rheumatology subset*	
142	Metabolic condition	106089007		

Additional terms for consideration	
Clinical Term	***Reason for suggested inclusion***

Those who have provided input at some point in time to the Draft Child Developmental Services Subset of SNOMED terms are:

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