

Definitions and operationalizations of pediatric chronic patients: A scoping review

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Online Recource 4: References to definitions

Online Recource 4A: Reference list Children with Medical Complexity (CMC)

Definition CMC (n=187)	
Definition according to Cohen et al. (2011)	(1-166)
Definition Cohen with additional information	(167-176)
Studies using other term patient category with definition Cohen et al. (n=11)	
Pediatric medical complexity	(177)
Medically complex children	(178-182)
Infants or neonates with medical complexity	(183-187)

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Online Resource 4B: Reference list Children and Youth with Special Health Care Needs (CYSHCN)

Definition CYSHCN (n=100)	
Definition McPherson et al. (1998)	(188-275)
Studies using other term patient category with definition McPherson et al. (n=12):	
Pediatric complex chronic care patients	(276)
Children with complex care needs	(277-282)
Children with complex health needs	(283-285)
Children with complex healthcare needs	(286, 287)
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Online Resource 4C: Reference list Chronic Complex Conditions (CCC)

Definitions CCC (n=45)	
Definition Feudtner et al. (2000)	(288-324)
Studies using other term patient category with definition Feudtner et al. (n=6)	
complex health conditions	(325)
children with complex medical needs	(326)
with life-limiting complex chronic conditions	(327)
pediatric home healthcare users	(328)
chronic complex health conditions	(329)
multiple complex chronic conditions	(330)
Additional information	
Mortality	(294)
High complex care	(291)
Neurological CCC	(288)
Second definition	
Definition Simon et al. (2010)	(331, 332)

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Online Resource 4D: Reference list Life Limiting Conditions (LLC)

Definitions LLC (n=32)	
Definition Fraser et al. (2012)	(333-348)
Definition Together for Short Lives (2018)	(349-364)
Studies using other term patient category with definition Together for Short Lives	
Non-malignant LCC	(349, 350)

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Online Resource 4E: Reference list Profound and Multiple Intellectual Disabilities (PMID)

Definition PMID (n=24)	
Definition Nakken & Vlaskamp (2002)	(365-383)
Studies using other term patient category with definitions PMID (n=5)	
Severe or profound intellectual and multiple disabilities	(384)
Children with significant cognitive and motor developmental delays (SDD)	(385)
Children with severe or profound intellectual disabilities (SPID)	(386) (387)
Children with polyhandicap	(388)
Complex and/or profound needs	

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Online Resource 4F: Reference list Pediatric Chronic Conditions (PCC)

Definitions PCC (n=21)	
Definition Mokkink et al. (2008)	(389-409)
Additional information	
Sociodemographic aspects of illness	397 (397)
Daily life limitations	(398-400, 404, 406)
Duration of disease	(397)
Psychological problems	(409)

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Online Resource 4G: Reference list Technology Dependence (TD)

Definition TD (n=10)	
Definition US Congress Office of Technology Assessment (OTA)	(410-416)
Studies using other term patient category with definitions TD (n=3)	
Medically complex, technology-dependent children	(417)
Children dependent on respiratory support	(418)
Children with invasive long-term ventilator dependence	(419)
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Definitions PCCI (n=9)	
Shapiro et al. (2017)	(420-426)
Definition Shapiro with additional information	(427)
Demirkiran et al. (2021)	(428)

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Online Resource 4I: Reference list Other Findings

Other findings (n=94)	(429-522)
Other patient categories (n=18)	
Children with physical disabilities	(429)
Children with disabilities	(430, 431)
Long stay patients	(432)
Medically fragile infants	(433, 434)
Genetic condition in children	(435)
Children with complex health conditions	(436)
Children with complex health needs	(437)
Children with complex medical needs	(438)
Children with complex chronic health conditions	(439)
Children with chronic illness and medical complexity	(440)
Children with multiple complex needs	(441)
Children with health complexities and special needs	(442)
Children with complex care needs	(443)
Children with palliative care needs	(444, 445)
Children with severe multiple disabilities	(446)
PCC definitions with considerable variation (n=21)	
Time indication	(447-464)
Medical care	(449-453, 458, 460-462, 465)
Daily life limitations	(449, 453, 460, 461, 464-466)
Quality of life	(447, 464)
Psychological problems	(458, 463, 467)
Definition used for other patient category (n=36)	
Population CMC with definition CCC	(468-479)
Population CMC with definition CYSHCN	(480-489)
Population CYSHCN with definition CMC	(490)
Population CCC with definition CMC	(491-493)
CYSHCN as a subset of CMC	(494-497)
Population TD with definition CMC	(498-500)
Population TD with definition Feudtner et al.(2005	(501-503)
Operationalization tools used as definition (n=19)	
CSHCN screener	(504, 505)
PMCA	(506-508)
CSHCN according to the SHCN screener Bethell et al.	(509-520)
Chronic conditions indicator	(521)
NSCH	(522)

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