

## Appendix 1 (as supplied by the authors): Search strategies

### MEDLINE strategy

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R)

- 1 adolescent/ or exp child/ or exp infant/
- 2 exp Pediatrics/
- 3 Minors/
- 4 or/1-3 [children]
- 5 \*Palliative Care/ec, mt, st, sn, td, ut [Economics, Methods, Standards, Statistics & Numerical Data, Trends, Utilization]
- 6 \*Hospice Care/
- 7 \*Terminal Care/ec, mt, st, sn, td, ut [Economics, Methods, Standards, Statistics & Numerical Data, Trends, Utilization]
- 8 \*Respite Care/
- 9 or/5-8 [Palliative Care narrow main topic]
- 10 4 and 9 [children and palliative care]
- 11 limit 10 to "review articles"
- 12 limit 10 to systematic reviews
- 13 limit 10 to meta analysis
- 14 systematic review?.mp.
- 15 Cochrane database of systematic reviews.jn.
- 16 or/14-15
- 17 10 and 16
- 18 or/11-13,17 [children and palliative care reviews] (
- 19 limit 18 to yr="1974 -Current" [reviews after 1974]
- 20 Adrenoleukodystrophy/
- 21 Alagille Syndrome/
- 22 Alexander Disease/
- 23 alpha-N-Acetylgalactosaminidase/df [Deficiency]
- 24 Argininosuccinic Aciduria/
- 25 Aspartylglucosaminuria/
- 26 Bartter Syndrome/
- 27 Canavan Disease/
- 28 Carbamoyl-Phosphate Synthase I Deficiency Disease/
- 29 "Congenital Disorders of Glycosylation"/
- 30 Carnitine O-Palmitoyltransferase/df [Deficiency]
- 31 Cholesterol Ester Storage Disease/
- 32 Citrullinemia/
- 33 Costello Syndrome/
- 34 Cri-du-Chat Syndrome/
- 35 De Lange Syndrome/

- 36 "Diffuse Cerebral Sclerosis of Schilder"/
- 37 DiGeorge Syndrome/
- 38 Farber Lipogranulomatosis/
- 39 Fucosidosis/
- 40 Gangliosidoses/
- 41 Gangliosidoses, GM2/
- 42 Glycogen Storage Disease Type II/
- 43 Glycogen Storage Disease Type IIb/
- 44 Glycogen Storage Disease Type IV/
- 45 Hereditary Central Nervous System Demyelinating Diseases/
- 46 Histiocytosis, Langerhans-Cell/
- 47 Huntington Disease/
- 48 Hyperglycinemia, Nonketotic/
- 49 Incontinentia Pigmenti/
- 50 Jacobsen Distal 11q Deletion Syndrome/
- 51 Kearns-Sayre Syndrome/
- 52 Klippel-Trenaunay-Weber Syndrome/
- 53 Lafora Disease/
- 54 Leigh Disease/
- 55 Lesch-Nyhan Syndrome/
- 56 Leukodystrophy, Globoid Cell/
- 57 Leukodystrophy, Metachromatic/
- 58 Lipidoses/
- 59 MELAS Syndrome/
- 60 Menkes Kinky Hair Syndrome/
- 61 MERRF Syndrome/
- 62 Methylmalonyl-CoA Mutase/df [Deficiency]
- 63 Mevalonate Kinase Deficiency/
- 64 Mitochondrial Encephalomyopathies/
- 65 Mitochondrial Myopathies/
- 66 Mucopolidoses/
- 67 Mucopolysaccharidosis I/
- 68 Mucopolysaccharidosis II/
- 69 Mucopolysaccharidosis III/
- 70 Mucopolysaccharidosis VII/
- 71 Multiple Acyl Coenzyme A Dehydrogenase Deficiency/
- 72 Multiple Sulfatase Deficiency Disease/
- 73 Myoclonic Epilepsies, Progressive/
- 74 Neuroaxonal Dystrophies/cn [Congenital]
- 75 Neuronal Ceroid-Lipofuscinoses/
- 76 niemann-pick disease, type a/ or niemann-pick disease, type b/ or niemann-pick disease, type c/
- 77 Oculocerebrorenal Syndrome/
- 78 Olivopontocerebellar Atrophies/

- 79 Ophthalmoplegia, Chronic Progressive External/
- 80 Ornithine Carbamoyltransferase Deficiency Disease/
- 81 Pelizaeus-Merzbacher Disease/
- 82 Peroxisomal Disorders/
- 83 Propionic Acidemia/
- 84 Pyruvate Carboxylase Deficiency Disease/
- 85 Pyruvate Dehydrogenase Complex Deficiency Disease/
- 86 Pyruvate Metabolism, Inborn Errors/
- 87 Refsum Disease/
- 88 Refsum Disease, Infantile/
- 89 Rett Syndrome/
- 90 Rubinstein-Taybi Syndrome/
- 91 Sandhoff Disease/
- 92 Sea-Blue Histiocyte Syndrome/
- 93 Sialic Acid Storage Disease/
- 94 Smith-Lemli-Opitz Syndrome/
- 95 Spasms, Infantile/
- 96 Sphingolipidoses/
- 97 sulfatidosis/
- 98 Unverricht-Lundborg Syndrome/
- 99 von Hippel-Lindau Disease/
- 100 Wolf-Hirschhorn Syndrome/
- 101 Wolman Disease/
- 102 Zellweger Syndrome/
- 103 Aicardi Syndrome/
- 104 Aicardi? Syndrome.mp.
- 105 alpha-N-Acetyl|galactosaminidase/df [Deficiency]
- 106 alpha-NAGA deficiency.mp.
- 107 alpha-Mannosidosis/
- 108 Argininosuccinic Aciduria/
- 109 Argininosuccinicaciduria.mp.
- 110 Argininosuccinate lyase deficiency.mp.
- 111 ASuria.mp.
- 112 ASL deficiency.mp.
- 113 ARSACS.mp.
- 114 Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay.mp.
- 115 beta-Mannosidosis/
- 116 Charlevoix-saguenay spastic ataxia.mp.
- 117 Dubowitz.mp.
- 118 Escobar Syndrome.mp.
- 119 Galactosidases/
- 120 Glutaric Acidemia Type I.mp.
- 121 Glutaric Aciduria Type I.mp.
- 122 Glutathione/df [Deficiency]

- 123 Infantile Neuroaxonal Dystrophy.mp. or Neuroaxonal Dystrophies/
- 124 Seitelberger's Disease.mp.
- 125 Jeune Thoracic Dystrophy.mp.
- 126 Asphyxiating Thoracic Dystrophy.mp.
- 127 Kanzaki Disease.mp.
- 128 Lennox-Gastaut Syndrome.mp.
- 129 3-methylcrotonyl-CoA carboxylase deficiency.mp.
- 130 Methylcrotonyl-CoA carboxylase deficiency.mp.
- 131 3-MCC deficiency.mp.
- 132 3MCC.mp.
- 133 MCC deficiency.mp.
- 134 Muscular Dystrophy, Duchenne/
- 135 exp Leukemia, Lymphoid/
- 136 Cerebral Palsy/
- 137 Neuroblastoma/
- 138 Muscular Atrophy, Spinal/
- 139 Neuroectodermal Tumors, Primitive/
- 140 Leukemia, Myeloid, Acute/
- 141 Mitochondrial Diseases/
- 142 Mitochondrial Diseases/
- 143 Friedreich Ataxia/
- 144 Osteosarcoma/
- 145 Trisomy 18.mp.
- 146 Medulloblastoma/
- 147 "Spinal Muscular Atrophies of Childhood"/ or SMA Type II.mp.
- 148 Pontine Glioma.mp.
- 149 Rett Syndrome/
- 150 Rhabdomyosarcoma/
- 151 Sarcoma, Ewing/
- 152 Brain Neoplasms/
- 153 Cystic Fibrosis/
- 154 Hypoxia-Ischemia, Brain/
- 155 Trisomy 13.mp.
- 156 Batten's Disease.mp.
- 157 Brain stem glioma.mp.
- 158 San Filippo Syndrome.mp.
- 159 Brain Stem Neoplasms/
- 160 CHARGE Syndrome/
- 161 Ependymoma/
- 162 Carcinoma, Hepatocellular/
- 163 exp HIV Infections/
- 164 Microcephaly/
- 165 Mitochondrial Diseases/
- 166 Adrenoleukodystrophy/

- 167 Biliary Atresia/
- 168 Glioblastoma/
- 169 Hodgkin Disease/
- 170 Hurler's syndrome.mp.
- 171 Leigh Disease/
- 172 Epilepsy/
- 173 Arthrogyrosis/
- 174 Astrocytoma/
- 175 Atypical Teratoid Rhabdoid Tumour.mp.
- 176 Burkitt Lymphoma/
- 177 Chromosome Aberrations/
- 178 Down Syndrome/
- 179 Dravet Syndrome.mp.
- 180 Glioblastoma/
- 181 Glutaric aciduria.mp.
- 182 Hydranencephaly/
- 183 Hypoplastic Left Heart Syndrome/
- 184 Krabbe Disease.mp.
- 185 Muscular Dystrophies, Limb-Girdle/
- 186 Metabolism, Inborn Errors/ or Metabolic Diseases/
- 187 Leukodystrophy, Metachromatic/
- 188 Mitochondrial enzyme complex IV.mp.
- 189 Mitochondrial Myopathies/
- 190 Enterocolitis, Necrotizing/
- 191 NYD.mp.
- 192 Pallister-Killian Syndrome.mp.
- 193 Pelizaeus-Merbacher Syndrome.mp.
- 194 Polymicrogyria.mp.
- 195 Propionic Acidemia/
- 196 Hypertension, Pulmonary/
- 197 Severe brain injury.mp.
- 198 Tay-Sachs Disease/
- 199 Wilms Tumor/
- 200 Chromosome Inversion/
- 201 Adams-Oliver Syndrome.mp.
- 202 Aicardi-Goutieres Syndrome.mp.
- 203 Alpers Syndrome.mp. or "Diffuse Cerebral Sclerosis of Schilder"/
- 204 Aminoacid decarboxylase deficiency.mp.
- 205 Anaplastic Astrocytoma.mp.
- 206 Brain/ab [Abnormalities]
- 207 Adrenoleukodystrophy/
- 208 Anomalous left coronary artery from pulmonary artery.mp.
- 209 Anterior Horn Cell Disease.mp.
- 210 Askin's Tumour.mp.

211 ATRT.mp.  
 212 Atypical Di George Syndrome.mp.  
 213 Menkes Kinky Hair Syndrome/ or Atypical Menkes.mp.  
 214 Lymphoma, B-Cell/  
 215 Rasmussen's Encephalitis.mp.  
 216 Ependymoma/  
 217 Burkitt Lymphoma/ or Burkett Lymphoma.mp.  
 218 Heart Neoplasms/  
 219 Cardiomyopathies/  
 220 Cerebral AV Malformation.mp.  
 221 Renal Insufficiency, Chronic/  
 222 Renal Insufficiency/  
 223 Chronic lung disease.mp.  
 224 Central Nervous System/ab [Abnormalities]  
 225 Heart Defects, Congenital/  
 226 "Tetralogy of Fallot"/ or Complex Tetralogy.mp.  
 227 De Lange Syndrome/  
 228 Dandy-Walker Syndrome/  
 229 severe neurological impairment.mp.  
 230 Failure to Thrive/  
 231 Neoplasms/  
 232 or/20-231  
 233 adolescent/ or exp child/ or exp infant/  
 234 exp Pediatrics/  
 235 Minors/  
 236 or/233-235  
 237 232 and 236  
 238 terminal care/ or hospice care/ or resuscitation orders/  
 239 \*Palliative Care/  
 240 \*Terminally Ill/  
 241 \*Respite Care/  
 242 \*Progressive Patient Care/  
 243 \*Long-Term Care/  
 244 or/238-243  
 245 237 and 244  
 246 limit 245 to "review articles"  
 247 limit 245 to systematic reviews  
 248 systematic review?.mp.  
 249 Cochrane database of systematic reviews.jn.  
 250 or/248-249  
 251 245 and 250  
 252 limit 245 to meta analysis  
 253 or/246-247,251-252 [reviews in LTC and palliative care]  
 254 limit 253 to yr="1974 -Current" [reviews after 1974]

255 19 or 254 [LTC and/or Children and Palliative care reviews after 1974]  
256 comment/ or editorial/ or letter/ or news/  
257 10 or 245  
258 257 not (255 or 256) [LTC and/or Children and Palliative care - primary articles total ]  
259 limit 258 to yr="2000 -Current" [LTC and/or Children and Palliative care - primary articles after 2000]

## **EMBASE strategy**

### Ovid EMBASE

- 1 adrenoleukodystrophy/
- 2 Alagille syndrome/
- 3 Alexander disease/
- 4 Fabry disease/
- 5 argininosuccinic aciduria/
- 6 aspartylglycosaminuria/
- 7 Bartter syndrome/
- 8 Canavan disease/
- 9 carbamoyl phosphate synthetase I deficiency/
- 10 "congenital disorder of glycosylation"/
- 11 Carnitine O-Palmitoyltransferase Deficiency.mp.
- 12 cholesterol ester storage disease/
- 13 citrullinemia/
- 14 Costello syndrome/
- 15 cat cry syndrome/
- 16 de Lange syndrome/
- 17 Schilder disease/
- 18 DiGeorge syndrome/
- 19 Farber disease/
- 20 fucosidosis/
- 21 gangliosidosis/
- 22 GM2 gangliosidosis/
- 23 glycogen storage disease type 2/
- 24 Danon disease/
- 25 glycogen storage disease type 4/
- 26 demyelinating disease/
- 27 Langerhans cell histiocytosis/
- 28 Huntington chorea/
- 29 hyperglycinemia/
- 30 incontinentia pigmenti/
- 31 Jacobsen syndrome/
- 32 Kearns Sayre syndrome/

- 33 angioosteohypertrophy syndrome/
- 34 myoclonus epilepsy/
- 35 Leigh disease/
- 36 Lesch Nyhan syndrome/
- 37 globoid cell leukodystrophy/
- 38 metachromatic leukodystrophy/
- 39 lipidosis/
- 40 MELAS syndrome/
- 41 Menkes syndrome/
- 42 MERRF syndrome/
- 43 Methylmalonyl-CoA Mutase Deficiency.mp.
- 44 mevalonate kinase deficiency/
- 45 mitochondrial encephalomyopathy/
- 46 mitochondrial myopathy/
- 47 mucopolysaccharidosis/
- 48 Hurler syndrome/
- 49 Sanfilippo syndrome/
- 50 mucopolysaccharidosis type 7/
- 51 multiple acyl CoA dehydrogenase deficiency/
- 52 multiple sulfatase deficiency/
- 53 myoclonus epilepsy/
- 54 neuroaxonal dystrophy/cn [Congenital Disorder]
- 55 neuronal ceroid lipofuscinosis/
- 56 Niemann Pick disease/
- 57 Lowe syndrome/
- 58 olivopontocerebellar atrophy/
- 59 chronic progressive external ophthalmoplegia/
- 60 ornithine transcarbamylase deficiency/
- 61 Pelizaeus Merzbacher disease/
- 62 "disorders of peroxisomal functions"/
- 63 propionic acidemia/
- 64 pyruvate carboxylase deficiency/
- 65 pyruvate dehydrogenase complex deficiency/
- 66 "disorders of carboxylic acid metabolism"/
- 67 Refsum disease/
- 68 infantile Refsum disease/
- 69 Rett syndrome/
- 70 Rubinstein syndrome/
- 71 Sandhoff disease/
- 72 histiocytosis/
- 73 sialic acid storage disease/
- 74 Smith Lemli Opitz syndrome/
- 75 infantile spasm/
- 76 lipidosis/



- 77 metachromatic leukodystrophy/
- 78 myoclonus epilepsy/
- 79 von Hippel Lindau disease/
- 80 Wolf Hirschhorn syndrome/
- 81 Wolman disease/
- 82 Zellweger syndrome/
- 83 Aicardi syndrome/
- 84 Aicardi? Syndrome.mp.
- 85 alpha-N-Acetylgalactosaminidase Deficiency.mp.
- 86 alpha-NAGA deficiency.mp.
- 87 mannosidosis/
- 88 argininosuccinic aciduria/
- 89 Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay.mp.
- 90 beta mannosidosis/
- 91 Dubowitz syndrome/
- 92 webbed neck/ or Escobar Syndrome.mp.
- 93 galactosidase/
- 94 Glutaric Acidemia Type I.mp.
- 95 Glutaric Aciduria Type I.mp.
- 96 Glutathione Deficiency.mp.
- 97 neuroaxonal dystrophy/
- 98 Jeune Thoracic Dystrophy.mp.
- 99 Asphyxiating Thoracic Dystrophy.mp.
- 100 Kanzaki Disease.mp.
- 101 Lennox Gastaut syndrome/
- 102 3-methylcrotonyl-CoA carboxylase deficiency.mp.
- 103 Methylcrotonyl-CoA carboxylase deficiency.mp.
- 104 3-MCC deficiency.mp.
- 105 3MCC.mp.
- 106 MCC deficiency.mp.
- 107 Duchenne muscular dystrophy/
- 108 exp lymphatic leukemia/
- 109 cerebral palsy/
- 110 neuroblastoma/
- 111 spinal muscular atrophy/
- 112 neuroectoderm tumor/
- 113 acute granulocytic leukemia/
- 114 "disorders of mitochondrial functions"/
- 115 Friedreich ataxia/
- 116 osteosarcoma/
- 117 trisomy 18/
- 118 medulloblastoma/
- 119 hereditary spinal muscular atrophy/
- 120 pontine glioma/

121 rhabdomyosarcoma/  
122 Ewing sarcoma/  
123 brain tumor/  
124 cystic fibrosis/  
125 hypoxic ischemic encephalopathy/  
126 trisomy 13/  
127 neuronal ceroid lipofuscinosis/  
128 Brain stem glioma.mp.  
129 brain stem tumor/  
130 syndrome CHARGE/  
131 ependymoma/  
132 liver cell carcinoma/  
133 Human immunodeficiency virus infection/  
134 microcephaly/  
135 "disorders of mitochondrial functions"/  
136 adrenoleukodystrophy/  
137 bile duct atresia/  
138 glioblastoma/  
139 Hodgkin disease/  
140 Leigh disease/  
141 epilepsy/  
142 arthrogryposis/  
143 astrocytoma/  
144 rhabdoid tumor/  
145 Burkitt lymphoma/  
146 chromosome aberration/  
147 Down syndrome/  
148 severe myoclonic epilepsy in infancy/  
149 glioblastoma/  
150 Glutaric aciduria.mp.  
151 hydranencephaly/  
152 hypoplastic left heart syndrome/  
153 globoid cell leukodystrophy/  
154 limb girdle muscular dystrophy/  
155 "inborn error of metabolism"/  
156 metabolic disorder/  
157 metachromatic leukodystrophy/  
158 Mitochondrial enzyme complex IV.mp.  
159 mitochondrial myopathy/  
160 necrotizing enterocolitis/  
161 NYD.mp.  
162 Pallister Killian syndrome/  
163 Pelizaeus Merzbacher disease/  
164 microgyria/

165 propionic acidemia/  
166 pulmonary hypertension/  
167 brain injury/  
168 Tay Sachs disease/  
169 neuroblastoma/  
170 chromosome inversion/  
171 Adams Oliver syndrome/  
172 Aicardi Goutieres syndrome/  
173 Alpers disease/  
174 Schilder disease/  
175 Aminoacid decarboxylase deficiency.mp.  
176 glioblastoma/  
177 brain malformation/  
178 adrenoleukodystrophy/  
179 coronary artery anomaly/  
180 anterior horn cell disease/  
181 Askin's Tumour.mp.  
182 ATRT.mp.  
183 DiGeorge syndrome/  
184 Menkes syndrome/  
185 B cell lymphoma/  
186 Rasmussen's Encephalitis.mp. (4)  
187 ependymoma/  
188 Burkitt lymphoma/  
189 heart tumor/  
190 cardiomyopathy/  
191 brain arteriovenous malformation/  
192 chronic kidney failure/  
193 kidney failure/  
194 chronic lung disease/  
195 central nervous system malformation/  
196 congenital heart malformation/  
197 Fallot tetralogy/  
198 de Lange syndrome/  
199 Dandy Walker syndrome/  
200 severe neurological impairment.mp.  
201 failure to thrive/  
202 exp \*neoplasm/  
203 or/1-202 [LTC]  
204 adolescent/  
205 exp child/  
206 exp infant/  
207 child\*.ti,ot,sh,hw,kw.  
208 infant?.ti,ot,sh,hw,kw.

209 adolescent?.ti,ot,sh,hw,kw.  
 210 exp pediatrics/  
 211 P?ediatric\*.ti,ot,sh,hw,kw.  
 212 exp juvenile/  
 213 minor?.ti,ot,sh,hw,kw.  
 214 youth?.ti,ot,sh,hw,kw.  
 215 teen?.ti,ot,sh,hw,kw.  
 216 or/204-215 [children broad strategy]  
 217 203 and 216 [LTC and Children]  
 218 hospice care/  
 219 terminal care/  
 220 \*palliative therapy/  
 221 \*terminally ill patient/  
 222 \*hospice patient/  
 223 \*respite care/  
 224 \*progressive patient care/  
 225 \*long term care/  
 226 (care adj3 (terminal or Palliative or hospice or respite or bereavement or end-of-life or terminally ill or dying)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]  
 227 (palliative adj3 (treatment\* or medicine or therap\* or care)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]  
 228 or/218-227 [palliative care broad search]  
 229 217 and 228 [Palliative care in children with LTC]  
 230 limit 229 to "systematic review"  
 231 limit 229 to meta analysis  
 232 Cochrane database of systematic reviews.mp.  
 233 systematic review?.mp.  
 234 232 or 233  
 235 229 and 234  
 236 limit 229 to evidence based medicine  
 237 or/230-231,235-236 [reviews EMBASE for palliative care in child with LTC]  
 238 limit 237 to yr="1974 -Current"  
 239 or/204-206,210-212 [Children specific search strategy]  
 240 or/218-223 [palliative care more specific strategy]  
 241 239 and 240 [children and palliative care]  
 242 limit 241 to "systematic review"  
 243 limit 241 to meta analysis  
 244 241 and 234  
 245 limit 241 to evidence based medicine  
 246 or/242-245 [reviews EMBASE for palliative care in child - more specific no key words]  
 247 limit 246 to yr="1974 -Current"  
 248 238 or 247

249 241 or 229 [ Palliative care in children and/or LTC total]  
250 comment/ or editorial/ or letter/ or news/  
251 249 not (248 or 250) [ Palliative care in children and/or LTC primary studies no reviews  
or comments]  
252 limit 251 to yr="2000 -Current" [LTC and/or Children and Palliative care - primary articles  
after 2000]

## CINAHL strategy

Search Terms	Search Options	Actions
S11	((((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care"))) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders")))) NOT (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7)	<b>Limiters</b> - Published Date: 20000101-20131231 <b>Search modes</b> - Boolean/Phrase
S10	((((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care"))) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders")))) NOT (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7)	<b>Limiters</b> - Published Date: 19900101-20131231 <b>Search modes</b> - Boolean/Phrase
S9	((((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care"))) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders")))) NOT (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7)	<b>Search modes</b> - Boolean/Phrase
S8	((((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care"))) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders")))) AND (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7)	<b>Search modes</b> - Boolean/Phrase
S7	((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care")) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders"))	<b>Limiters</b> - Publication Type: Statistics <b>Search modes</b> - Boolean/Phrase
S6	((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care")) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders"))	<b>Limiters</b> - Publication Type: Review <b>Search modes</b> - Boolean/Phrase
S5	((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric	<b>Limiters</b> - Publication Type: Meta Synthesis

	Units+") OR (MH "Pediatric Care")) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders"))	<b>Search modes</b> - SmartText Searching
S4	((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care")) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders"))	<b>Limiters</b> - Publication Type: Meta Synthesis <b>Search modes</b> - Boolean/Phrase
S3	((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care")) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders"))	<b>Limiters</b> - Publication Type: Meta Analysis <b>Search modes</b> - SmartText Searching
S2	((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care")) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders"))	<b>Limiters</b> - Publication Type: Masters Thesis <b>Search modes</b> - SmartText Searching
S1	((MH "Child") OR (MH "Infant") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR (MH "Pediatric Units+") OR (MH "Pediatric Care")) AND ((MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Resuscitation Orders"))	<b>Limiters</b> - Publication Type: Systematic Review <b>Search modes</b> - Boolean/Phrase

## LILACS strategy

"cuidado PALIATIVO" or "tratamento PALIATIVO" or "cuidado PALIATIVO a doentes terminais" or "cuidados PALIATIVOs" or "programas de cuidados PALIATIVOs" or "cuidados PALIATIVOs na terminalidade da vida" or "cuidados INTERMITENTES" or "programas de cuidados INTERMITENTES" [Descritor de assunto] and "hospitais pediatricos" or "PEDIATRIA" or "crianca" or "cuidado da crianca" or "saude da crianca" or "servicos de saude da crianca" or "crianca pos-termo" or "crianca pre-escolar" or "criancas" or "criancas pre-escolares" or "ADOLESCENTE" or "ADOLESCENTES" [Descritor de assunto]

## Grey literature

Organization/Conference	Website
American Academy of Hospice and Palliative Medicine (AAHPM)	<a href="http://www.aahpm.org/resources/">http://www.aahpm.org/resources/</a>
American Academy of Pediatrics (AAP)	<a href="http://www.aap.org/">http://www.aap.org/</a>
American Cancer Society	<a href="http://www.cancer.org">www.cancer.org</a>
Association for Children with LifeThreatening or Terminal Conditions and their Families (ACT)	<a href="http://www.act.org.uk">http://www.act.org.uk</a>
Center to Advance Palliative Care	<a href="http://www.capc.org">www.capc.org</a>
Children's Hospice and Palliative Care Organization	<a href="http://www.childrenshospice.org">http://www.childrenshospice.org</a>
Children's Hospice International (CHI)	<a href="http://www.chionline.org">http://www.chionline.org</a>
Children's Oncology Group	<a href="http://www.childrensoncologygroup.org">www.childrensoncologygroup.org</a>
ChiPPS of the National Hospice and Palliative Care Organization	
Children's Project on Palliative/Hospice Services (ChiPPS)	<a href="http://www.nhpc.org/resources/pediatric-hospice-and-palliative-care">http://www.nhpc.org/resources/pediatric-hospice-and-palliative-care</a>
City of Hope Pain & Palliative Care Resource Center (COHPPRC)	<a href="http://www.cityofhope.org/PRC/">http://www.cityofhope.org/PRC/</a>
Education in Palliative and End-of-Life Care (EPEC)	<a href="http://www.epec.net/">http://www.epec.net/</a>
End of Life Nursing Education Curriculum	<a href="http://www.aacn.nche.edu/ELNEC">www.aacn.nche.edu/ELNEC</a>
End-of-Life/Palliative Education Resource Center (EPERC)	<a href="http://www.eperc.mcw.edu/">http://www.eperc.mcw.edu/</a>



Hospice and Palliative Nurses Association	<a href="http://www.hpna.org">www.hpna.org</a>
National Alliance for Children with Life-Threatening Conditions	<a href="http://www.nacwltc.org">http://www.nacwltc.org</a>
National Consensus Project on Quality Palliative Care	<a href="http://www.nationalconsensusproject.org">http://www.nationalconsensusproject.org</a>
The Children's Room	<a href="http://www.childrensroom.org">www.childrensroom.org</a>
The Initiative for Pediatric Palliative Care (IPPC)	<a href="http://www.ippcweb.org/">http://www.ippcweb.org/</a>
CAPC National Seminar 2012 - posters	<a href="http://www.capc.org/capc-resources/capc-poster-sessions/">http://www.capc.org/capc-resources/capc-poster-sessions/</a>
Canadian Hospice Palliative Care Association	<a href="http://www.chpca.net/">http://www.chpca.net/</a>
International Congress in Palliative Care	<a href="http://www.palliativecare.ca/en/index.html">http://www.palliativecare.ca/en/index.html</a>
Canadian Network of Palliative Care for Children	<a href="http://cnpcc.ca/">http://cnpcc.ca/</a>