

Estimating the prevalence of life-limiting conditions in Queensland for children and young people aged 0-21 years using health administration data

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1 **Key question summary**

2 *What is known about the topic?*

3 Data from the UK indicate that the prevalence of life-limiting conditions amongst children
4 and young people is increasing. However, such data is not available for the Australian
5 population. As prevalence data can be influenced by population characteristics, it is
6 important to establish country-specific epidemiological data rather than extrapolating data
7 from other countries. Country-specific data can inform health planners and policy makers
8 of the scale of the problem from a geographical and demographic context. This is essential
9 for Australia given the diverse geographical and demographic characteristics and specific
10 needs of the Aboriginal and Torres Strait Islander populations.

11

12 *What does this paper add?*

13 This study is the first to provide an estimation of the prevalence of life-limiting conditions
14 in children and young people aged 0 to 21 years in Queensland, Australia. Estimates
15 include the prevalence of life-limiting conditions in children and young people who
16 identify as being of Aboriginal and/or Torres Strait Islander descent.

17

18 *What are the implications for practitioners?*

19

20 Prevalence of life-limiting conditions in Queensland is greater than previously thought.
21 There is a need to grow both a generalist and specialist paediatric palliative care workforce
22 in response to this increasing prevalence. The estimates of prevalence proportions from
23 this study provide the foundation on which future health service activities can be built as
24 they provide country-specific clinical and demographic characteristics.

25

26 **Abstract**

27 **Background:** The prevalence of life-limiting conditions in children in Australia is
28 unknown. Such data are needed to inform health service planning for paediatric palliative
29 care.

30 **Aim:** To estimate the prevalence of life-limiting conditions for children and young
31 people aged 0 to 21 years living in Queensland, Australia.

32 **Design:** Observational study using linked administrative health data from the 2011 and
33 2016 calendar years.

34 **Setting/participants:** All individuals with an International Classification of Diseases and
35 Related Health Problems, Tenth Revision, Australian Modification code relating to a life-
36 limiting condition eligible for palliative care, recorded against an admission to a public or
37 private Hospital and Health Service in Queensland, Australia, or recorded against a cause
38 or underlying cause of death in the Queensland Registrar General Deaths.

39 **Results:** The overall prevalence of life-limiting conditions per 10,000 population
40 increased from 35.2 (95% CI 34.2 to 36.2) in 2011 to 43.2 (95% CI 42.1 to 44.4) in 2016.
41 This increase in prevalence was greatest for children less than 1 year of age and for those
42 who identified as Aboriginal and/or Torres Strait Islander.

43 **Conclusion:** The estimation of the number of children and young people with life-limiting
44 conditions can inform health service planning for paediatric palliative care in Queensland,
45 Australia. Future research is needed to identify the number of children and young people
46 with a life-limiting conditions who do not have an admitted episode.

47

48 **Keywords:**

49 Palliative care, paediatrics, prevalence, observational study, state health planning

50 Australia, oceanic ancestry group

51

52

53 **Introduction**

54 **Background**

55 In 2016, the worldwide figure for the number of 0 to 19 year olds living with a condition
56 needing palliative care was estimated to be at least 21 million.⁽¹⁾ Conditions include those
57 which are life-threatening, where a cure is possible but can fail, such as some cancers, and
58 life-limiting conditions, where there is no cure, such as Duchenne muscular dystrophy,
59 severe cerebral palsy and HIV.⁽²⁾ Paediatric palliative care is an active approach to the
60 holistic care of children with such conditions and the support of their families.⁽³⁾

61 Despite the global need for paediatric palliative care⁽¹⁾ and the rising prevalence of life-
62 limiting conditions in children and young people⁽⁴⁻⁷⁾, readily available prevalence data to
63 inform health service planning in Australia are not available. The prevalence proportion
64 for England of 32 per 10,000 population,⁽⁶⁾ is referred to when estimating prevalence for
65 Australia. As prevalence proportions can differ according to ethnicity, geographical area,
66 age, gender, socioeconomic status and type of life-limiting condition,^(4-6, 8) to effectively
67 inform health service planning, country specific prevalence estimates are required to
68 understand the clinical and demographic characteristics of the population.^(5, 9)

69 In Queensland Australia, there is one statewide paediatric palliative care service covering
70 1,730,648 square kilometres of mainland and island areas.⁽¹⁰⁾ The service provides holistic

71 support to children and families whose needs are persistent and complex. The service also
72 provides support and education to other health professionals providing care and support to
73 children and families where the needs may be less complex and fluctuating.⁽¹¹⁾ When
74 planning for paediatric palliative care in Queensland, the geography and size of the state
75 poses particular challenges for health service planners, particularly in rural and remote
76 areas where lower access to health, education and employment services contribute to
77 poorer health status.⁽¹²⁾ Furthermore, as Aboriginal and/or Torres Strait Islander peoples in
78 general have lower access to health interventions, have poorer health outcomes and have
79 more hospital admissions than people who are not of Aboriginal and/or Torres Strait
80 Islander descent⁽¹³⁾, consideration needs to be given to the specific cultural and historical
81 factors which impact the health outcomes of Aboriginal and Torres Strait Islander
82 peoples.⁽¹⁴⁾

83 This study provides an estimation of the prevalence of life-limiting conditions in children
84 and young people aged 0 to 21 years living in Queensland, Australia using Queensland
85 Health administration data.

86

87 **Methods**

88 *Ethics approval*

89 This study received ethical approval from Children's Health Queensland Human Research
90 Ethics Committee EC00175 on 21 August 2017, reference HREC/17/QRCH/128 and
91 Queensland University of Technology EC00171 on 28 August 2017, reference
92 1700000796.

93

94 *Identification of life-limiting conditions*

95 The Directory of Life-Limiting Conditions⁽¹⁵⁾ was used to identify conditions eligible for
96 palliative care. The Directory contains most life-limiting conditions⁽¹⁶⁾, “for which curative
97 treatment may be feasible but can fail”⁽¹⁷⁾ and most life-threatening conditions “ for which
98 there is no reasonable hope of cure and from which children will die”.⁽¹⁷⁾ In Australia, the
99 International Classification of Diseases and Health Related Problems, Tenth Revision,
100 Australian Modification (ICD-10-AM)⁽¹⁸⁾ is used for morbidity coding and the
101 International Classification of Diseases and Health Related Problems, Tenth Revision
102 (ICD-10) for mortality coding. All codes contained in the Directory of Life-Limiting
103 Conditions were cross checked to the Australian Modification codes with the exception of
104 C97 “malignant neoplasms of independent (primary) multiple sites”,⁽¹⁹⁾ which is only used
105 as a morbidity code. Life-limiting conditions are coded under their primary sites as per the
106 codes listed in ICD-10-AM.⁽¹⁸⁾

107 Due to coding lag time, the 2016 death data had not been coded with ICD-10 codes. Text
108 search terms devised using the Directory of Life-Limiting Conditions⁽¹⁵⁾ along with
109 associated synonyms were used to identify deaths eligible for inclusion. To refine the
110 search terms for 2016, test searches were conducted by the Queensland Statistical Service
111 Branch using the 2011 death data, which had both ICD-10 codes and text terms.

112 *Data collections*

113 Individuals eligible for inclusion were identified from the Queensland Hospital Admitted
114 Patient Data Collection, Queensland Perinatal Data Collection and Queensland Registrar
115 General Deaths. The Queensland Hospital Admitted Patient Data Collection and
116 Queensland Perinatal Data Collection data collection include data from public and private

117 hospitals in Queensland. The Registrar General Deaths lists deaths occurring in
118 Queensland. The three data sets were linked by patient identification number and where
119 relevant admission episode. Data collections for the 2011 and 2016 calendar years were
120 used. The 2016 data were the most recent available and the 2011 data were used as a 5 year
121 comparator.

122 *Inclusion criteria*

123 All children and young people aged 0 to 21 years living in Queensland with an eligible life-
124 limiting condition recorded against an admitted episode or listed as a cause or underlying
125 cause of death from any of the three data collections at any time during the 2011 and 2016
126 calendar years.

127 *Data extraction*

128 Data were extracted in December 2017 by the Queensland Health Statistical Services
129 Branch. Data to estimate prevalence were provided as six separate data sets. These related
130 to, admission demographic characteristics, admission morbidity codes, main perinatal data,
131 perinatal morbidity codes, perinatal congenital anomaly codes and death data.

132

133 *Data management*

134 Individual data sets were manually checked for obvious errors and data not eligible for
135 inclusion removed. Where more than one eligible morbidity code were documented against
136 a single admission episode, the data were changed from long format to wide format for
137 ease of data merging. Individual data sets were merged using IBM SPSS® Version 25.⁽²⁰⁾
138 The admission demographic characteristic data set were used as the primary data set to
139 which all other data were merged. Patient identification number and where available

140 admission episode, were used to match individual records across the individual data sets.
141 Once all individual data sets were merged 50 records were checked at random against each
142 individual data set to check for merging errors. No merging errors were identified. First
143 admission episode was selected for each patient identification number following
144 completion of checks for accuracy.

145 *Defining population characteristics*

146 The Queensland Paediatric Palliative Care Service receives referrals for individuals aged
147 0 to 18 years. However, as it can take around three years to transition young people to adult
148 services, during which time paediatric and adult palliative care services are delivered in
149 parallel, the 0 to 21 years age range was chosen for this study to capture individuals in the
150 transition period.

151 First admission episode for each calendar year was used for determining age, gender and
152 condition classification for individuals who only had an admitted episode or who had an
153 admitted episode and a death record. For individuals who died during 2011 or 2016, but
154 had no admitted episode, age at time of death and first condition recorded as a life-limiting
155 condition at time of death were reported. State of residence was determined using first
156 admission for those who had an admission record and at time of death for those without an
157 admission episode.

158 To ensure individuals could not be identified, life-limiting conditions were reported
159 according to their ICD-10-AM chapter classifications. Overarching classification of
160 conditions for life-limiting conditions were also reported as oncological, for conditions
161 classified as neoplasm and as non-oncological for all other chapter classifications, with the

162 exception of those recorded under ‘factors influencing health status and contact with health
163 services’. It was not possible to determine overarching classification of factors influencing
164 health status and contact with health services as they were only coded as palliative care.

165 *Data analysis*

166 Prevalence proportions were calculated by dividing the total number of individuals with a
167 life-limiting condition for the time-period of interest (numerator) by the total number of
168 individuals in the population for the same time point of interest (denominator), multiplied
169 by the proportion that is, 10,000 for prevalence per 10,000 population.⁽²¹⁾ An online
170 epidemiological calculator⁽²²⁾ was used to calculate 95% Confidence Intervals and to check
171 prevalence proportion calculations. The denominator was compiled using the 2011
172 Australian Bureau of Statistics Census TableBuilder.⁽²³⁾

173

174 **Results**

175 *Sample population*

176 A total of 4,529 children and young people aged 0 to 21 years living in Queensland with a
177 life-limiting condition were identified between 1 January 2011 and 31 December 2011. Of
178 the total, 4,500 were identified by admission episode and 13 by death record only. In
179 addition, eight children and young people had a linked record for admission and
180 cause/underlying cause of death where only the death record indicated a life-limiting
181 condition. A further eight individuals were identified as having a cause or underlying cause
182 of death listed as a life-limiting condition which matched to a life-limiting condition
183 recorded for an admission in 2010.

184 From 1 January 2016 and 31 December 2016, a total of 5,765 children and young people
185 aged 0 to 21 years were identified as living in Queensland with a life-limiting condition.
186 Of the total, 5,739 were identified from admission data and eight from death data only. A
187 further seven individuals were identified who had a cause/underlying cause of death listed
188 as a life limiting condition and who had a life-limiting condition recorded for admission
189 episodes prior to 2016. In addition, 11 individuals were identified who had a
190 cause/underlying cause of death recorded as a life/limiting condition but no life-limiting
191 condition identified on any admission in 2016.

192 The population at risk identified using the Australian Bureau of Statistics Census data⁽²³⁾
193 were 1,288,376 for 2011 and 1,333,650 for 2016.

194

195 *Missing data*

196 Comparison of the 2016 and 2011 death data extracted by text terms revealed
197 discrepancies. For 2011, 23 deaths identified by the text search were not identified by ICD-
198 10 codes. These mainly related to cerebral palsy or epilepsy. In addition, 11 deaths were
199 identified by ICD-10 codes but not by text search. Of the 11 deaths, eight had an
200 undetermined cause of death.

201 Gender and Indigenous status at time of death were not provided with death data. Gender
202 and Indigenous status at time of death were missing for 13 children and young people who
203 did not have an admitted episode in 2011 and for eight in 2016. Indigenous status were also
204 recorded as unknown/not stated for 174 children and young people in 2011 and for 104 in
205 2016. It was not possible to determine overarching classification of condition (non-
206 oncological or oncological) for two children and young people from 2011 and eight from

207 2016. Individuals with missing variables were excluded from prevalence calculations for
208 those variables. Their exclusion was negligible.

209

210 *Prevalence*

211 Overall prevalence increased from 35.2 per 10,000 population (95% CI 34.2 to 36.2) in
212 2011, to 43.2 per 10,000 population (95% CI 42.1 to 44.4) in 2016 (Table 1).

213 Prevalence was greatest for children less than 1 year of age. The prevalence proportion per
214 10,000 population was 237.2 (95% CI 225.1 to 250.0) in 2011 and 291.0 (95% CI 277.2 to
215 350.5) in 2016. The increase in prevalence proportion for those less than one year of age
216 was also the greatest increase for any one age group (Table 1). From 2011 to 2016,
217 prevalence of life-limiting conditions increased for all age groups except for children aged
218 7 to 9 years, for which the prevalence decreased by 1.1 per 10,000 population (Table 1).

219

220 [Insert Table 1]

221

222 For both years prevalence of life-limiting conditions were greater for males. However, the
223 increase in prevalence between the two calendar years were slightly greater for females
224 than males, rising from 32.0 per 10,000 population (95% CI 30.6 to 33.4) in 2011, to 40.6
225 (39.1 to 47.2) in 2016 (Table 2).

226

227 [Insert Table 2]

228

229 Table 3 provides a comparison of the prevalence of life-limiting conditions per ICD-10-
230 AM chapter. For 2011 and 2016, prevalence was greatest for conditions classified as
231 congenital malformations, deformations and chromosomal abnormalities. From 2011 to
232 2016, prevalence increased for all chapter classifications, with the exception of disorders
233 of the digestive system, for which there was a slight decrease (0.1 per 10,000 population).
234 The greatest increase in prevalence was for conditions classified as congenital
235 malformations, deformations and chromosomal abnormalities, increasing from 7.9 per
236 10,000 population (95% CI 7.4 to 7.8) in 2011, to 11.4 (95% CI 10.9 to 12.0) in 2016.

237

238 [Insert Table 3]

239

240 The increase in non-oncological conditions was greatest with an increase of 7.7 per 10,000
241 population. Increasing from 30.7 per 10,000 population (95% CI 29.8 to 31.7) in 2011, to
242 38.4 per 10,000 population (95% CI 37.3 to 39.4) in 2016. Oncological conditions
243 increased from 4.5 per 10,000 population (95% CI 4.1 to 4.8) in 2011 to 4.9 per 10,000
244 population (95% CI 4.5 to 5.2) in 2016, an increase of 0.5 per 10,000 population (Figure
245 1).

246

247 [Insert Figure 1]

248

249 Of the total sample population, the prevalence of life-limiting conditions for children and
250 young people who identified as being of Aboriginal and/or Torres Strait Islander descent
251 was 2.6 per 10,000 population (95% CI 2.4 to 2.9) in 2011 and 4.1 per 10,000 population

252 (95% CI 3.7 to 4.4) in 2016. This equated to an increase of 1.5 per 10,000 population.
253 However, when prevalence of life-limiting conditions is calculated using the total
254 Queensland Aboriginal and Torres Strait Islander population as the population at risk, the
255 prevalence is much greater. Prevalence for 2011 were 41.8 per 10,000 (95% CI 37.6 to
256 46.5) and for 2016 were 58.7 per 10,000 (95% CI 54.0 to 63.8), which is an increase of
257 16.9 per 10,000 population (Figure 2).

258

259 [Insert Figure 2]

260

261

262 **Discussion**

263 This study identified overall prevalence of life limiting conditions for children and young
264 people aged 0 to 21 years increased from 35.2 per 10,000 population (95% CI 34.2 to 36.2)
265 in 2011, to 43.2 per 10,000 population (95% CI 42.1 to 44.4) in 2016. As data from 2012
266 to 2015 were not analysed, the increase cannot be reported as a trend. However, the increase
267 is consistent with reports of the increasing prevalence of life-limiting conditions in other
268 countries⁽⁴⁻⁷⁾. As the Queensland prevalence estimates for 2011 and 2016 were greater than
269 those of England (32 per 10,000),⁽⁶⁾ it means that where England prevalence proportions
270 have been used to estimate current and projected population estimates for health service
271 planning in Queensland, figures are underestimated.

272 Based on the total Queensland Aboriginal and Torres Strait Islander population, the
273 prevalence for children and young people who identified as being of Aboriginal and or

274 Torres Strait Islander decent, in 2011 and 2016, was greater than that of the overall
275 prevalence. Previous research has suggested that when compared to Caucasians,
276 individuals from ethnic minority groups have higher prevalence of life-limiting
277 conditions.⁽⁵⁾ Further research is needed to establish the reasons. It is also essential for
278 health service planners, health professionals and Indigenous health workers to continue to
279 work with Aboriginal and Torres Strait Islander communities to develop models of care
280 that will meet the unique palliative care needs of Aboriginal and Torres Strait Islander
281 peoples.

282 The higher prevalence of life-limiting conditions for children less than 1 year of age is
283 consistent with the existing literature.^(4, 6, 7) However, when considering the prevalence
284 proportions for children less than 1 year of age, the majority of children included in the
285 numerator were ≤ 1 month old. For 2011, there were 1,078 (79.1%) children and for 2016
286 there were 1251 (78.9%) (data not shown). This is important as a large number of children
287 with life-limiting conditions die within the first month of life.^(24, 25) Although it would
288 beneficial to report prevalence proportions for those ≤ 1 month, this was not possible as
289 the lowest age for census data were recorded as 0 years. The higher prevalence of life-
290 limiting conditions found for males is also consistent with the current literature,⁽⁴⁻⁶⁾ as is
291 the greater prevalence for conditions classified as congenital malformations, deformations
292 and chromosomal abnormalities and those classified as non-oncological.^(5, 6)

293 While advances in medical care and technology can partially explain the increase in life-
294 limiting conditions,⁽²⁶⁻²⁹⁾ the incidence of life-limiting conditions needs to be determined
295 to better understand the proportion of children who are living longer and the proportion of
296 new cases.⁽²¹⁾ This will enable health service planners to develop sustainable paediatric and

297 adult palliative care services that meet demand and population need across a large and
298 geographically diverse state. Comprehensive data will also help inform the development
299 needs of the paediatric palliative care workforce to include number of professionals and
300 their education and training needs.

301 *Strengths and limitations*

302 This study is the first to estimate prevalence of life-limiting conditions in Queensland, one
303 of the largest states in Australia, using administrative health data. The population was
304 identified using linked data which was considered the best available. Error rates for data
305 linkage were equal to or less than five per thousand records. Individuals eligible for
306 inclusion were identified using an internationally recognised disease classification system.
307 However, we acknowledge there may be life-limiting conditions not included in the
308 Directory of Life-Limiting Conditions. Text searches and data extraction were carried out
309 by the Queensland Health Statistical Service Branch.

310 The use of secondary data meant data accuracy were influenced by quality and
311 completeness. Furthermore, data were limited to individuals who were admitted to a
312 Queensland Hospital and Health Service, or who died in Queensland. Other sources of data
313 were considered to identify individuals who did not have an admitted episode or diagnosis,
314 but due to the complex nature of the public and private health systems in Australia, and the
315 poor quality of the data, these options were not deemed feasible. Prevalence proportions
316 are likely underestimated due to the limitations of the data sources used.

317 Death text terms were coded with ICD-10 codes by the researcher who is not a trained
318 coder. Any causes or underlying causes of death which were not clearly identifiable as

319 relating to an ICD-10 code, were referred to the Paediatric Palliative Care Staff Specialist
320 for coding opinion. Therefore, differences in coding may exist.

321 These results should be extrapolated to other Australian populations with caution as
322 prevalence proportions can be influenced by clinical and demographic characteristics.^{(4-6,}
323 8)

324

325 **Conclusion**

326 The prevalence of life-limiting conditions in Queensland for 2016 was estimated to be 43.2
327 per 10,000 population (95% CI 42.1 to 44.4). This is greater than previously thought.
328 Prevalence was greatest for children less than one year of age, for those with congenital
329 malformations, deformations and chromosomal abnormalities and for those who identified
330 as being of Aboriginal and or Torres Strait Islander descent. These should be priority target
331 groups for paediatric palliative care health service planning in Queensland.

332

333 **References**

334

- 335 1. Connor SR, Downing J, Marston J. Estimating the global need for palliative care
336 for children: A cross-sectional analysis. *Journal of Pain and Symptom Management.*
337 2016;53(2):171-7.
- 338 2. Association for Children's Palliative Care & Royal College of Paediatrics and
339 Child Health. A guide to the development of children's palliative care services: ACT and
340 RCPCH; 1997 [Available from:
341 http://www.rcpch.ac.uk/sites/default/files/asset_library/Publications/G/Children's_Palliati
342 [ve_Care_Services.pdf](http://www.rcpch.ac.uk/sites/default/files/asset_library/Publications/G/Children's_Palliati).

- 343 3. World Health Organization. WHO definition of palliative care for children 2017
344 [Available from: <http://www.who.int/cancer/palliative/definition/en/>.
- 345 4. Fraser L, Jarvis S, Moran N, Aldridge J, Parslow R, Beresford B. Children in
346 Scotland requiring palliative care: Identifying numbers and needs (the chisp study). York:
347 University of York; 2015.
- 348 5. Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA, et al. Rising
349 national prevalence of life-limiting conditions in children in England. *Pediatrics*.
350 2012;129(4):e923-e9.
- 351 6. Fraser LK, Miller M, Aldridge J, McKinney PA, Parslow RC. Life-limiting and
352 life-threatening conditions in children and young people in the United Kingdom; national
353 and regional prevalence in relation to socioeconomic status and ethnicity: Final report for
354 Children's Hospice UK October 2011 Leeds, UK: Universtiy of Leeds; 2011 [Available
355 from:
356 [http://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Children](http://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Childrens_Hospices_UK_-_Ethnicity_Report.pdf)
357 [s_Hospices_UK_-_Ethnicity_Report.pdf](http://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Childrens_Hospices_UK_-_Ethnicity_Report.pdf).
- 358 7. Norman P, Fraser LK. Prevalence of life-limiting conditions in children and
359 young people in England: Time trends by area type. *Health & Place*. 2014;26:171-9.
- 360 8. Fraser LK, Lidstone V, Miller M, Aldridge J, Norman P, McKinney PA, et al.
361 Patterns of diagnoses among children and young adults with life-limiting conditions: A
362 secondary analysis of a national dataset. *Palliative Medicine*. 2014;28(6):513-20.
- 363 9. Queensland Health. Guide to health service planning. 3 ed. Brisbane: State of
364 Queensland; 2015.
- 365 10. Geoscience Australia. Area of Australia - states and territories 2017 [Available
366 from: [http://www.ga.gov.au/scientific-topics/national-location-](http://www.ga.gov.au/scientific-topics/national-location-information/dimensions/area-of-australia-states-and-territories)
367 [information/dimensions/area-of-australia-states-and-territories](http://www.ga.gov.au/scientific-topics/national-location-information/dimensions/area-of-australia-states-and-territories).
- 368 11. Palliative Care Australia. Palliative care service development guidelines 2018
369 [Available from: [http://palliativecare.org.au/wp-](http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf)
370 [content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf](http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf).
- 371 12. Eagar K, Garrett P, Lin V. Health planning: Australian perspectives. Crows Nest,
372 NSW: Allen & Unwin; 2001.

- 373 13. Queensland Health. Aboriginal and Torres Strait Islander patient care guide.
374 Brisbane: Queensland Health; 2014.
- 375 14. Department of Health and Ageing. National Aboriginal and Torres Strait Islander
376 health plan 2013-20232013; (June 14, 2016). Available from:
377 <https://www.health.gov.au/internet/main/publishing.nsf/content/B92E980680486C3BCA>
378 [257BF0001BAF01/\\$File/health-plan.pdf](https://www.health.gov.au/internet/main/publishing.nsf/content/B92E980680486C3BCA257BF0001BAF01/$File/health-plan.pdf).
- 379 15. Hain R, Devins M. Directory of life-limiting conditions Cardiff, 2011 [Available
380 from:
381 http://www.togetherforshortlives.org.uk/assets/0000/7089/Directory_of_LLC_v1.3.pdf.
- 382 16. Hain R, Devins M, Hastings R, Noyes J. Paediatric palliative care: Development
383 and pilot study of a 'directory' of life-limiting conditions. *BMC Palliative Care*.
384 2013;12(43).
- 385 17. Association for Children's Palliative Care & Royal College of Paediatrics and
386 Child Health. A guide to the development of children's palliative care services: ACT and
387 RCPCH; 1997 [Available from:
388 [http://www.rcpch.ac.uk/sites/default/files/asset_library/Publications/G/Children's Palliative](http://www.rcpch.ac.uk/sites/default/files/asset_library/Publications/G/Children's_Palliative_Care_Services.pdf)
389 [_Care_Services.pdf](http://www.rcpch.ac.uk/sites/default/files/asset_library/Publications/G/Children's_Palliative_Care_Services.pdf).
- 390 18. National Centre for Classification in Health (Australia). The international
391 statistical classification of diseases and related health problems, tenth revision, Australian
392 modification (ICD-10-AM). 7th ed. Lidcombe, NSW: National Centre for Classification
393 in Health; 2010.
- 394 19. World Health Organization. International statistical classification of diseases and
395 related health problems, 10th revision, volume 2 instruction manual 2016 [5th:[Available
396 from: https://icd.who.int/browse10/Content/statichtml/ICD10Volume2_en_2016.pdf.
- 397 20. IBM Corp. IBM SPSS statistics for Windows. Version 25.0 ed. Armonk, NY:
398 IBM Corp; 2017.
- 399 21. Gordis L. *Epidemiology*. 5th ed. Philadelphia, PA: Elsevier Saunders; 2014.
- 400 22. Dean AG, Sullivan KM, Soe MM. Open source statistics for public health 2013
401 [Available from: <https://www.openepi.com/Proportion/Proportion.htm>.
- 402 23. Australian Bureau of Statistics. Census TableBuilder 2018 [Available from:
403 <http://www.abs.gov.au/websitedbs/D3310114.nsf/Home/2016%20TableBuilder>.

- 404 24. National Institute for Health and Care Excellence. End of life care for infants,
 405 children and young people with life-limiting conditions: Planning and management
 406 (NG61). London: National Institute for Health and Care Excellence; 2016.
- 407 25. World Health Organization. Global health observatory data repository - mortality
 408 and global health estimates - child mortality 2016 [Available from:
 409 <http://apps.who.int/gho/data/node.main.ChildMort?lang=en>.
- 410 26. Abbott D, Carpenter J. ‘Wasting precious time’: Young men with Duchenne
 411 muscular dystrophy negotiate the transition to adulthood. *Disability & Society*.
 412 2014;29(8):1-14.
- 413 27. Cook K, Siden H, Jack S, Thabane L, Browne G. Up against the system: A case
 414 study of young adult perspectives transitioning from pediatric palliative care. *Nursing
 415 Research and Practice*. 2013;2013(2013).
- 416 28. Herbert A, Bradford N, Donovan L, Pedersen LA, Irving H. Development of a
 417 state-wide pediatric palliative care service in australia: Referral and outcomes over two
 418 years. *Journal of Palliative Medicine*. 2014;17(3):288-95.
- 419 29. Kerr H, Price J, Nicholl H, O’Halloran P. Transition from children’s to adult
 420 services for young adults with life-limiting conditions: A realist review of the literature.
 421 *International Journal of Nursing Studies*. 2017;76:1-27.

422
 423 Table 1
 424 *Comparison of prevalence proportions per 10,000 population by age group for period*
 425 *prevalence 2011 and 2016*

Age (years)	2011			2016			Difference ^b
	Prevalence ^a	95% CI		Prevalence ^a	95% CI		
		LL	UL		LL	UL	
<1	237.2	225.1	250.0	291.0	277.2	350.5	53.8
1 to 3	38.9	36.1	41.9	37.8	35.1	40.1	-1.1
4 to 6	28.1	25.8	30.7	40.1	37.4	43.1	12.0
7 to 9	21.4	19.3	23.7	26.2	24.1	28.6	4.8
10 to 12	20.0	18.0	22.2	26.3	24.0	28.7	6.3
13 to 15	19.8	17.8	22.0	27.8	25.4	30.3	8.0
16 to 18	25.9	23.7	28.4	35.0	32.4	37.9	9.1
19 to 21	27.0	27.4	29.5	35.6	33.0	38.4	8.6
Overall	35.2	34.2	36.2	43.2	42.1	44.4	8.0

426 *Note.* CI = confidence interval; LL = lower limit; UL = upper limit.
 427 ^aPrevalence proportion per 10,000 population; ^bDifference in prevalence proportion per 10,000
 428 population from 2011 to 2016.

429 Table 2
430 *Comparison of prevalence proportions per 10,000 population by gender for period*
431 *prevalence 2011 and 2016*

Gender	2011			2016			Difference ^b
	Prevalence ^a	95% CI		Prevalence ^a	95% CI		
		LL	UL		LL	UL	
Male	37.9	36.5	39.5	45.6	44.0	47.2	7.7
Female	32.0	30.6	33.4	40.6	39.1	42.2	8.6

432 *Note.* CI = confidence interval; LL = lower limit; UL = upper limit.

433 ^aPrevalence proportion per 10,000 population; ^bDifference in prevalence proportion per 10,000
434 population from 2011 to 2016.

435

436 Table 3
437 *Comparison of prevalence proportions per 10,000 population by ICD-10-AM chapter for*
438 *period prevalence 2011 and 2016*

ICD-10-AM Chapter	2011			2016			Difference ^b
	Prevalence ^a	95% CI		Prevalence ^a	95% CI		
		LL	UL		LL	UL	
Neoplasms	4.4	4.1	4.8	4.9	4.5	5.2	0.5
Diseases of the blood and blood forming organs and certain disorders involving the immune system	2.2	2.0	2.5	2.5	2.2	2.8	0.3
Endocrine, nutritional and metabolic diseases	3.6	3.3	4.0	4.0	3.6	4.3	0.4
Mental and behavioural disorders	0.1	0.1	0.2	0.2	0.2	0.3	0.1
Diseases of the nervous system	7.0	6.5	7.4	7.8	7.3	8.3	0.8
Disorders of the circulatory system	0.5	0.4	0.6	0.5	0.4	0.6	0.0
Disorders of the respiratory system	1.6	1.4	1.9	1.8	1.6	2.1	0.2
Disorders of the digestive system	0.5	0.4	0.6	0.4	0.3	0.5	-0.1
Diseases of musculoskeletal system and connective tissue	0.1	0.1	0.2	0.2	0.1	0.3	0.1
Diseases of the genitourinary system	2.1	1.9	2.4	3.3	3.0	3.6	1.2
Certain conditions originating in the perinatal period	4.8	4.5	5.2	5.9	5.5	6.2	1.1
Congenital malformations, deformations and chromosomal abnormalities	7.9	7.4	8.4	11.4	10.9	12.0	3.5

Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	0.2	0.1	0.2	0.2	0.1	0.3	0.0
Injury, poisoning and certain other consequences of external causes	*0.5	*0.3	*1.1	*0.7	*0.4	*1.4	*0.2
Factors influencing health status and contact with health services	*0.2	*0.0	*0.6	*0.6	*0.3	*1.1	*0.4
Certain infectious and parasitic diseases	*0.3	*0.1	*0.8	*0.7	*0.4	*1.4	*0.4
Disorders of the eye and adnexa	*0.1	*0.0	*0.4	*0.3	*0.1	*0.8	*0.2

439 *Note.* ICD-10-AM = International Statistical Classification of Diseases and Related Health
 440 Problems 10th Revision Australian Modification. CI = confidence interval; LL = lower limit; UL
 441 = upper limit. ^aPrevalence proportion per 10,000 population, unless marked with * which are
 442 reported as per 100,000 population; ^bDifference in prevalence proportion from 2011 to 2016 per
 443 10,000 population, unless marked with * which are reported as per 100,000 population.

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