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-threating 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% CI10.9 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 decent

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.

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

357   _s_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-

367   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-

370   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.

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_Palliati

389   ve_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   [a]Prevalence proportion per 10,000 population; [b]Difference 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*

| | 2011 | | | 2016 | | | |
| | | 95% CI | | | 95% CI | | |
Gender	Prevalence[a]	LL	UL	Prevalence[a]	LL	UL	Difference[b]
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 [a]Prevalence proportion per 10,000 population; [b]Difference 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*

| | 2011 | | | 2016 | | | |
| | | 95% CI | | | 95% CI | | |
ICD-10-AM Chapter	Prevalence[a]	LL	UL	Prevalence[a]	LL	UL	Difference[b]
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. [a]Prevalence proportion per 10,000 population, unless marked with * which are
442 reported as per 100,000 population; [b]Difference 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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