



Reaching Every Family in Scotland



**Medical Director to CHAS
21 September 2018**

‘A radical new collaborative culture’

‘The goal must be nothing less than a thorough transformation of our public services. The prize is a sustainable person centred system achieving outcomes for every person and citizen.’

‘Commission on the Future delivery of Public Services.’

Christie Commission 2011



Children's Hospices Across Scotland

Definition of Children's Palliative Care

Palliative care for children and young people (CYP) with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond.

It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the CYP and support for their family.

It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Together for Short Lives (2013)



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Strategic Framework for Action on Palliative and End of Life Care

2016-2021

Supporting Evidence Summary



The Scottish Government

December 2015



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SFA: 10 Commitments

3. Support the development of a new palliative and end of life care educational framework.

4. Support and promote the further development of holistic palliative care for the 0-25 years age group.

7. Seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations.



Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)



Loena Frisic
Stuart Jarvis
Nicola Moran
Jan Aldridge
Roger Parlow

UNIVERSITY of York
The Department of Health, Sciences

SRU Social Policy



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SOHL Social Policy

- **To identify the number of babies, children and young people with life-limiting or life-threatening conditions**
- **To describe this population in terms of their ages, conditions/diagnoses, geographic locations and ethnicity**
- **To generate evidence of their psychosocial care needs**



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- **More children with palliative care needs**
- **Children under 1 year a priority**
- **Age specific services for 16-25 year olds**
- **Services to ensure access to care in areas of higher deprivation, be culturally sensitive**
- **Improved psychological, emotional and domestic support**



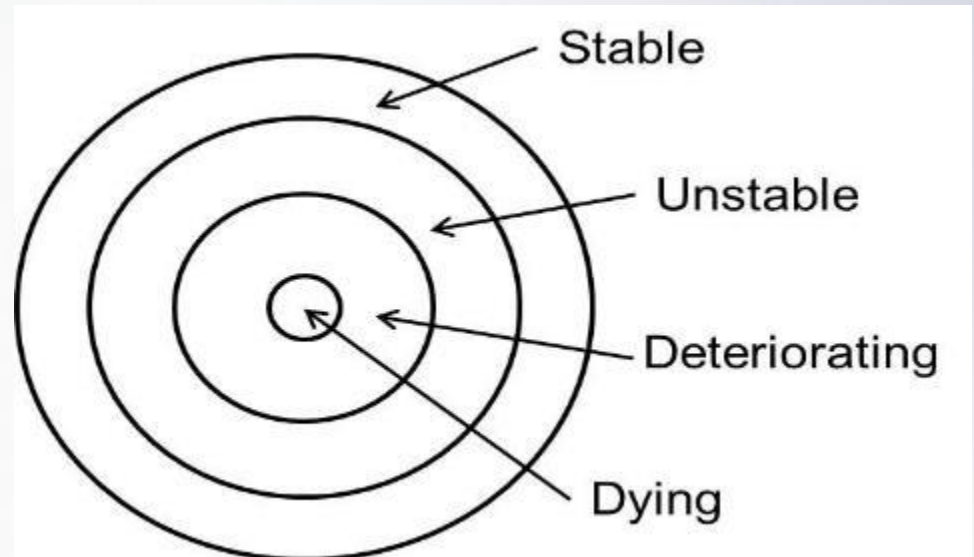
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- **By 2021, everyone in Scotland who needs palliative care will have access to it**
- **Support and promote the further development of holistic palliative care for the 0 – 25 years age group**



The scale of unmet need?

- **Total number of children 15404 in Scotland**
- **Stable**
- **Unstable**)
- **Deteriorating**) **2201**
- **Dying** (195))
- **4774 (0-5 yrs)**





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The children and families we must reach in Scotland by 2020

Abbie

The doctors thought Abbie would never live to see her fifth birthday. Today she is 11, and still a fighter. We will not let Abbie and her family struggle alone.



15,404 with life-shortening conditions

6,600 hospital contacts

2,200 classified as unstable or deteriorating

195 children and young people die each year

Erin My

Erin's mum recently told us, 'CHAS have helped us do things as a family that we never thought possible.' We're going to make sure Erin's family continue to share precious time together.



Christian

Christian's parents have to live every day with the knowledge that he could die at any time. We are there for them now. And we'll continue to be there for as long as they need us.



4,783 children under five



When Zoë was born the doctors told Heather and her husband, Gerry, to enjoy every day they had with her. We're helping them all to make sure that's exactly what they do.

Zoë

A Scottish charity and a company limited by guarantee Scottish charity number SC 036704. Registered in Scotland number 136420.



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The numbers of babies, children and young people

There are over **15,400** children and young people (under 25 years old) in Scotland with an underlying condition from which they may die, and just under **4,800** of these are 0-5 years old.



Additionally:

● = 0-5 years old

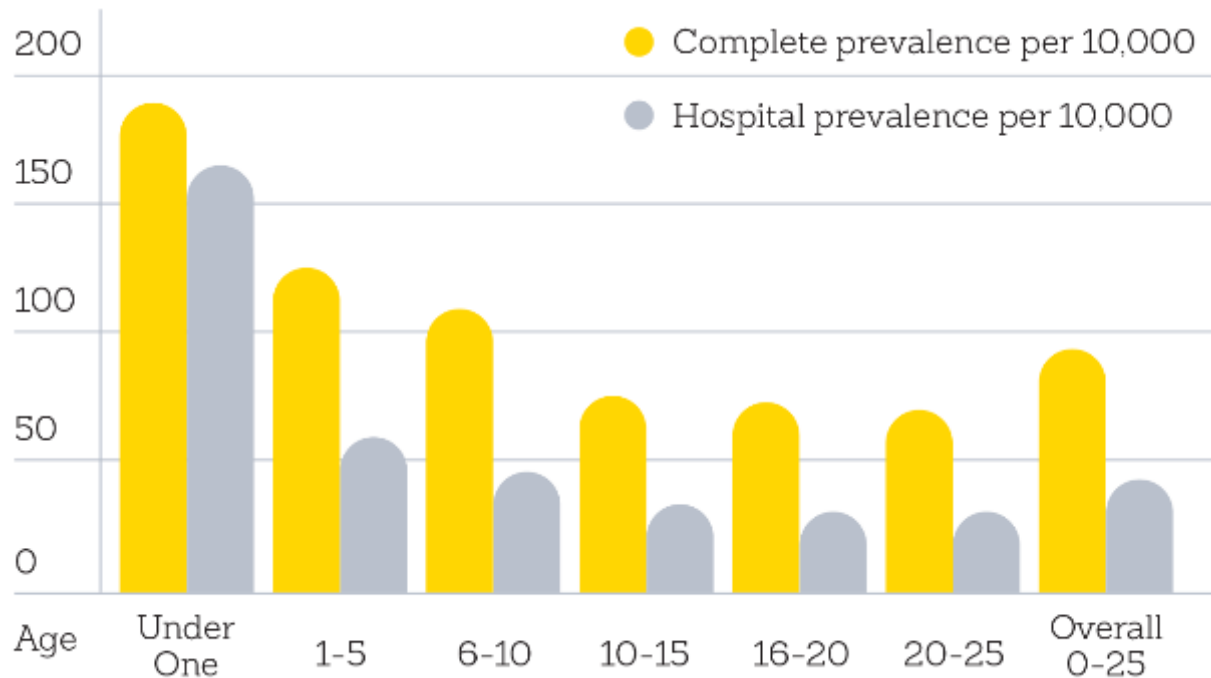
- **6,600** of those children have received secondary or tertiary care within the last year
- **2,200** are known to be either unstable or deteriorating
- **195** die each year



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The ages of babies, children and young people

The ChiSP Study tells us the complete and (hospital) prevalence for each age group is (2013/14):



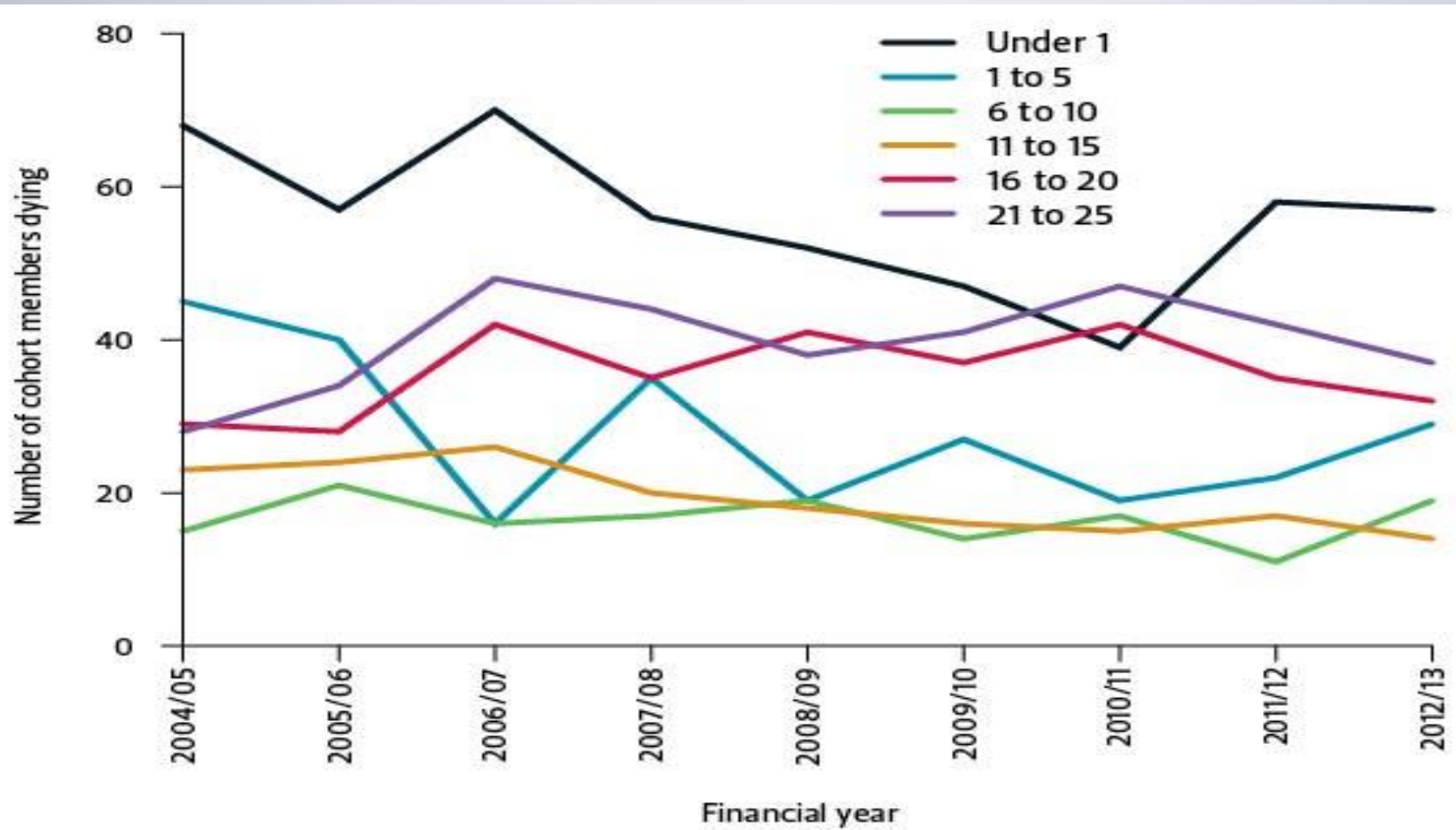
Prevalence decreases by age group until 10-15 years of age when it stabilises, but the largest group by far is the under five year old cohort.

This evidences why CHAS will focus its immediate work on developing services for 0-5 year age group.



Children's Hospices Across Scotland

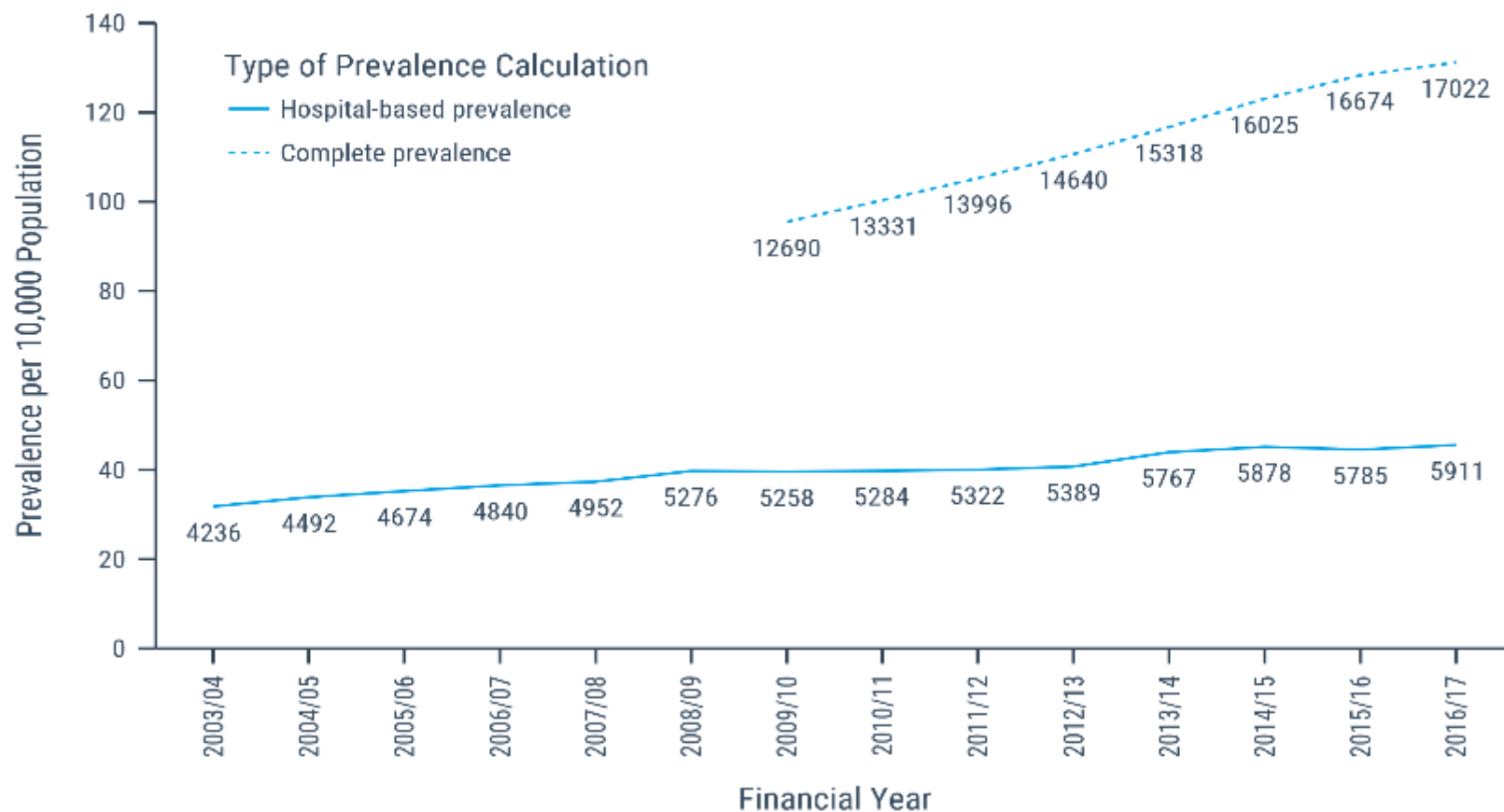
Deaths by Age



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Overall

Hospital-based and complete prevalence of life-limiting conditions among children and young people
0-21 years
Scotland
2003/04 - 2016/17



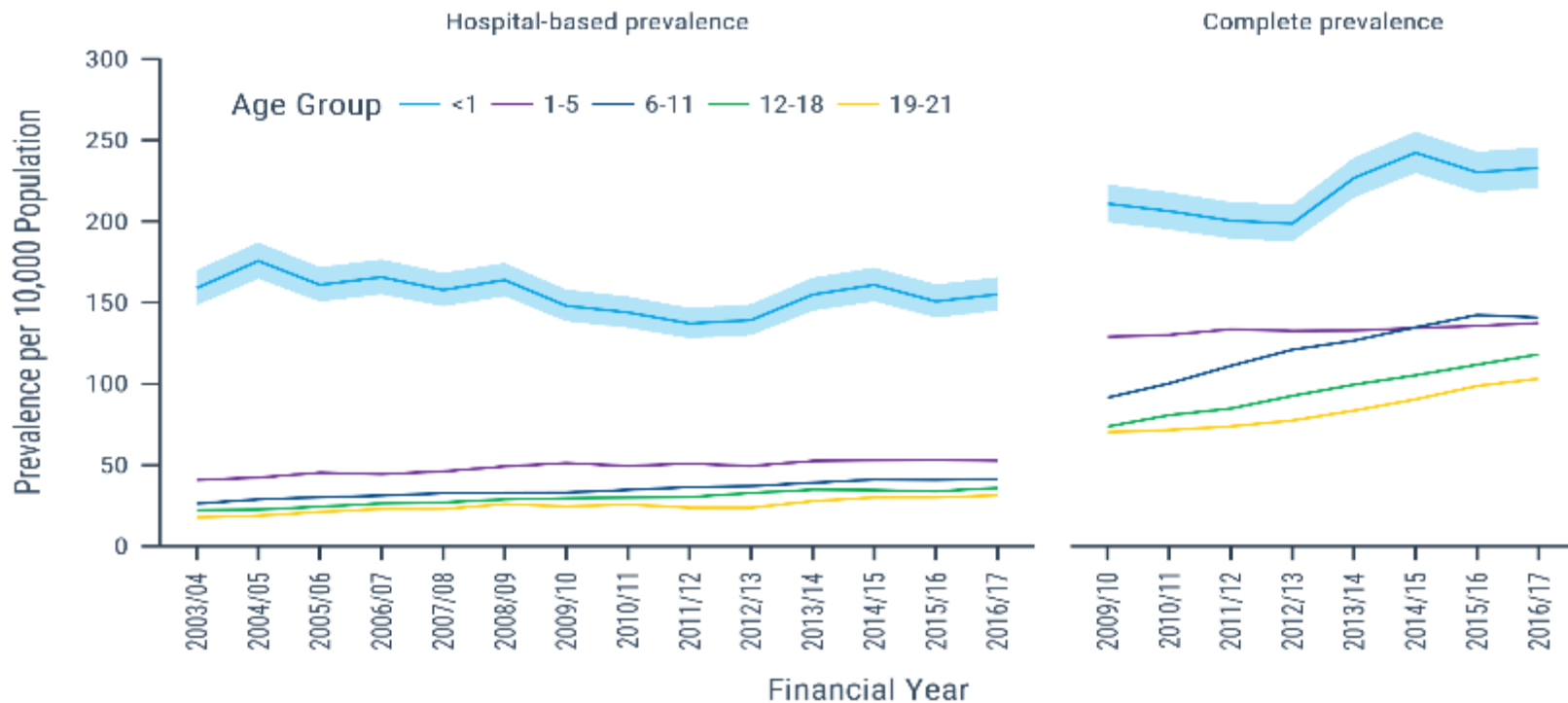
Produced by NHS National Services Scotland (Ref. XRB17031)



Children's Hospices Across Scotland

By age group

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by age group
 Scotland
 2003/04 - 2016/17



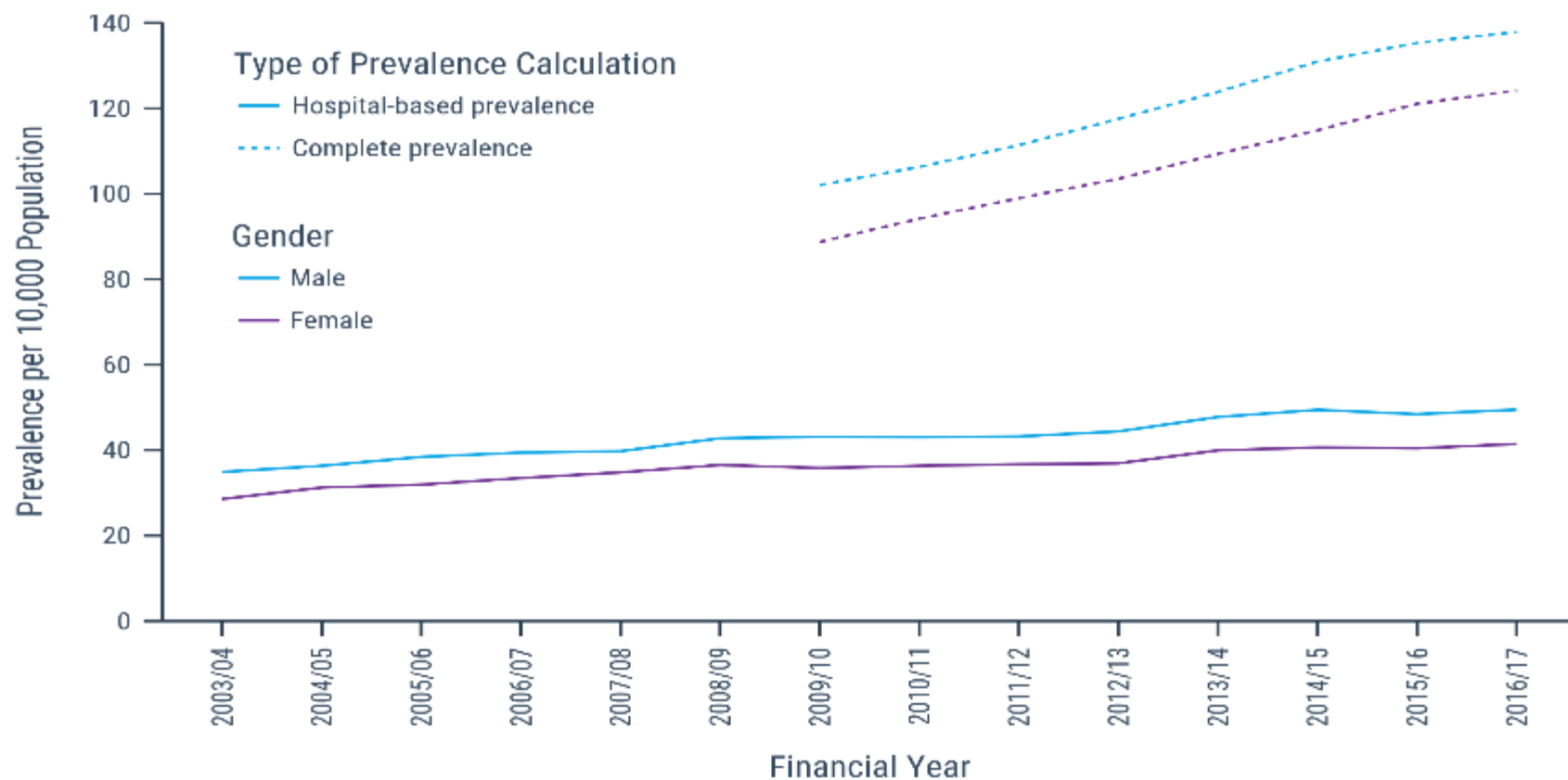
Shaded regions indicate 95% confidence interval
 Produced by NHS National Services Scotland (Ref. XRB17031)



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By gender

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years; by gender (excluding Not Known)
Scotland
2003/04 - 2016/17



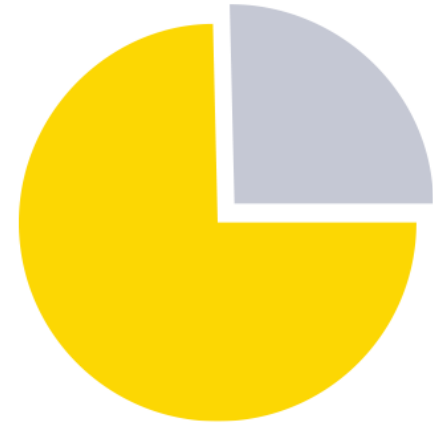
Produced by NHS National Services Scotland (Ref. XRB17031)



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The prevalence of life-limiting conditions is highest amongst the most deprived in our communities

26% of all the babies, children and young people with life-limiting conditions live in the most deprived areas of Scotland.



Prevalence of life-limiting conditions is highest among those of South Asian ethnicity

CHAS services will offer culturally competent and sensitive care to children from all ethnic groups.



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21st International Congress on
Palliative Care
21^e Congrès international sur les
soins palliatifs

October 18-21
Du 18 au 21 octobre
2016
MONTRÉAL

At Home, Hospice and Palliative care – a Country's, a Province's, and a State's Approach to Serving Children Far From the Medical Center

Pat Carragher, Children's Hospice Association of Scotland
Hal Siden, Canuck Place Children's Hospice, BC, Canada
Ken Pituch, Hospice of Michigan, USA

Canada

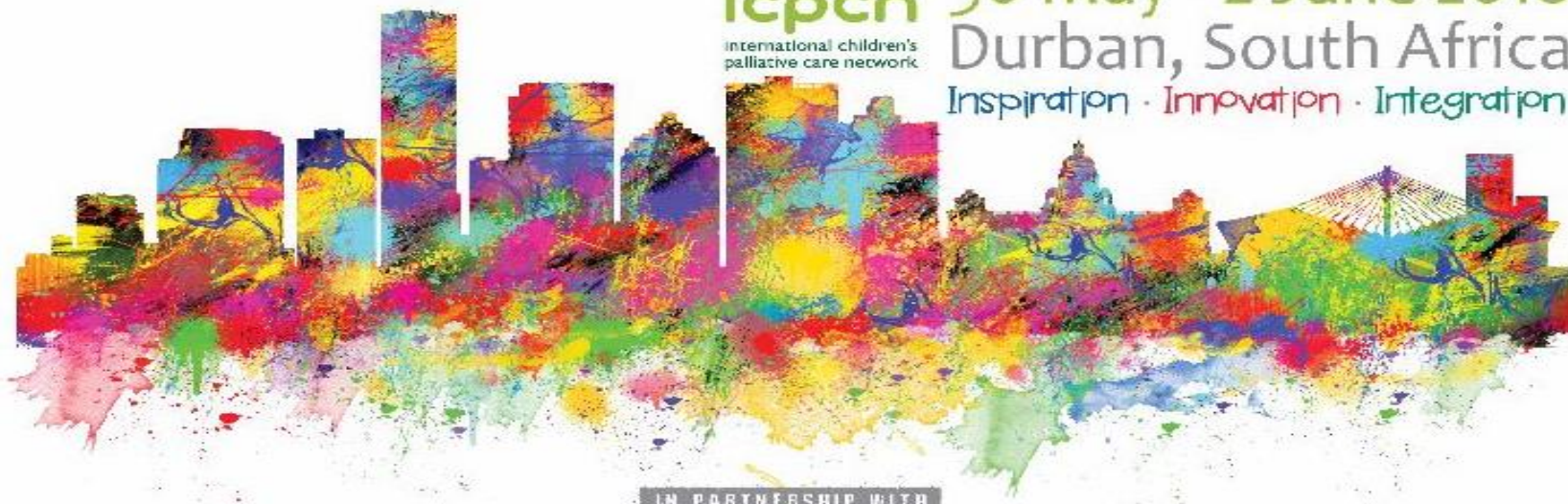


Children's Hospices Across Scotland

3RD ICPCN CONFERENCE : INSPIRATION, INNOVATION, INTEGRATION



3rd ICPCN Conference
30 May - 2 June 2018
Durban, South Africa
Inspiration · Innovation · Integration



IN PARTNERSHIP WITH



umduduzi
Hospice Care for Children



HPCA
CARE & SUPPORT
Hospice Palliative Care Association of South Africa



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The stand out needs of families

- **Families need and value specialist emotional support**
- **Parents report that the demands of domestic tasks and keeping up with the care routine can overwhelm family life**
- **Specialist residential provision is valued by parents and children alike**
- **We can do more to alleviate families experiences of discrimination in their communities and social isolation**
- **Parents want to continue to be mum and dad at the end of life and that is not always made possible in clinical settings**



Challenges

- Early palliative care*
- Offering genuine choice
- Skilling and availability of workforce
- Scalability
- ACP
- Transition
- Geography and settings
- Research and education

* http://www.leeds.ac.uk/news/article/4173/the_benefits_of_earlier_access_to_palliative_care







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REALISING REALISTIC MEDICINE



- 47% of babies, children and young people who died under the age of 16 years are under one year old
- > 90% of the under one age group died in hospital





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“ The death of a child has serious and lasting effects on their parents, siblings and other family members, effectively for the rest of their lives.

Any attempt to reduce symptoms and to improve the quality of life in the final days and weeks, must not only be good for the child involved but, in the fullness of time in the fullness of time, be helpful for those left behind.”



Children's Hospices Across Scotland



Keep the joy alive

www.chas.org.uk     SupportCHAS

Children's Hospices Across Scotland is a trading name of Children's Hospice Association Scotland. Scottish charity number SC 019724.



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21 September 2018**