



**CHILDREN IN  
WALES REQUIRING  
PALLIATIVE CARE:  
TRENDS IN  
PREVALENCE AND  
COMPLEXITY  
2009 - 2019**



## FOREWORD

In the trajectory of every new clinical service, there comes a point when it is no longer enough for those responsible for developing and funding it to be motivated by moral conviction, and we need to turn instead to data.

It would be hard to say exactly when that moment arrives. Almost by definition, a novel specialty is novel precisely because no-one has previously thought to look for the evidence that it is necessary. Any new way for healthcare to serve patients starts, not because there is data to suggest it is needed, but because someone has observed that we are not treating patients as well as we should, and on that basis has decided that things should be done differently. The need for a novel service is a moral assertion, based on compassion and common humanity. Evidence, if you like, of a sort; but evidence based on reasoning, not on data.

Several things are needed for a service to get beyond that embryonic stage. First of all, a funder must be found who is willing to support initial development on the basis of conviction alone, until the service finds itself in a position to measure its own increasing activity as its reach extends. Since the Sugar Report in 2009, paediatric palliative care in Wales has enjoyed exactly that kind of support from the Welsh Government and we now use a bespoke suite of metrics and outcome measures to collect data prospectively.

But such 'in house' data can only tell us about the children our service is already reaching. As the numbers augment year on year, it becomes impossible to avoid

the inference that there are other children whom we are not reaching, and might not even be aware of. It is an inevitable blind spot because, of course, we cannot know how much we don't know. And that's where paediatric palliative care in Wales has really fallen on its feet. Thanks again to support from the Welsh Government we have been able to engage the services of Professor Lorna Fraser and her team from the University of York. In the report that follows, Professor Fraser's research has been able to tell us about other children with life-limiting conditions. The ones even Wales' well-developed palliative care service doesn't see. Children whose families do not need specialist palliative medicine, but do need the wider palliative and short break care that children's hospices can offer. Children who do need specialist palliative care, but cannot access it because of the nature of their diagnosis or where they live. Complex children on dozens of different medications, whose exhausted parents manage medical devices in the home for years or decades. Thanks to this report, we no longer have to guess how many children in Wales might need to access palliative care. We now know that the number is well over four thousand (that's rather more children than have diabetes), and that the number is rising steadily year on year. We know that children with life-limiting conditions live in every area in Wales; not just those within reach of acute paediatric departments, or with good community children's nursing support. We know that they are among the most medically complex children in Wales. And we know that, as so often, the burden is falling most heavily on those least able to bear it financially.

That data powerfully informs how we deliver children's palliative care services, not only in hospital and at home but also in the Children's Hospices in Wales who can provide the spaces, places and resources that allow children and young people to thrive. The data allows children's hospices both to refine and to target their services, focusing on areas of Wales where there is most need for their services, and enables them to engage politically by providing a base for discussions with decision- and lawmakers in order to facilitate the best possible service for children and young people with life-limiting conditions in Wales.

Does all this data mean that paediatric palliative care in Wales has come of age? That we are ready to set aside moral assertions about what is needed and henceforth develop palliative care services for children wholly in response to data? Well, no, not quite yet. For the time being, the argument for development of paediatric palliative care services is still, at least partly, a moral one. We should still be appalled by a degree of inequity in Wales that means a child dying at home from a metabolic disease can only access specialist palliative care nursing between 9 and 5 during the week, while an adult, or a child dying from cancer, can have 24-hour access. We should be outraged that in Betsi Cadwaladr and Aneurin Bevan there are palliative care nurses for adults, but none for children, and that in Powys there is no children's palliative care provision whatsoever. These are matters of right and wrong; of fair and unfair; of justice and injustice. We do not need data to know they must be urgently redressed.

But a last push to get us to the evidence-base starting line need not take long. Once it is done, the data in this report mean that paediatric palliative care in Wales will at last be able to follow in the footsteps of its sister specialty in adults, and finally move forward in a direction that is shaped, not only by compassion and the demands of justice, but also and increasingly by objective evidence. We may not have reached the starting blocks quite yet but, thanks to the data in this report, when we do so we will already be running.

Our thanks go to Lorna Fraser and Stuart Jarvis from the University of York for undertaking the huge amount of work needed to complete this project. Thanks must also go to the NHS Wales National Palliative and End of Life Care Programme Board for funding the project, and the steering group for navigating the work through inception to publication.

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## INTRODUCTION

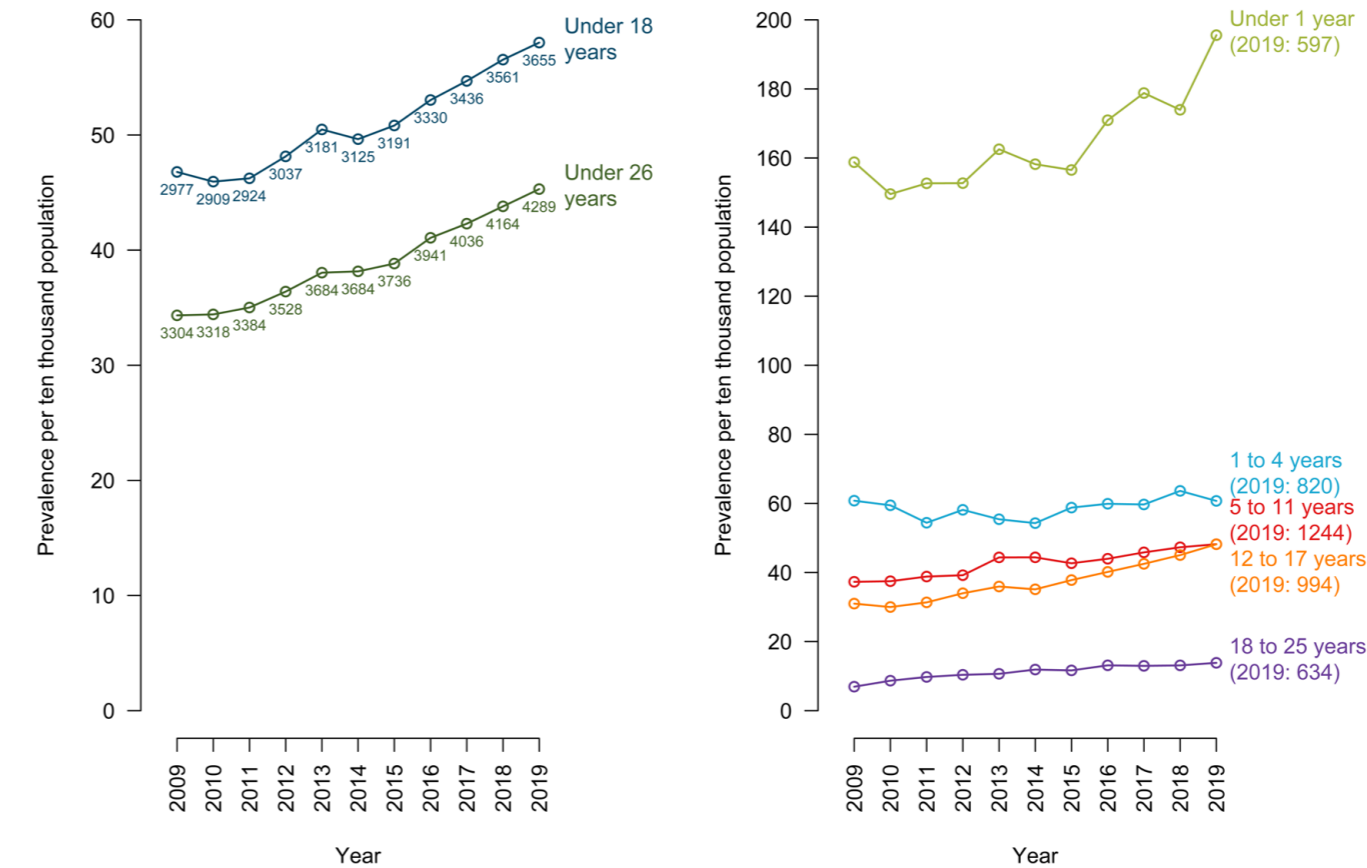
Knowing about the community you serve is a vital part of providing services to those in need. This study provides everyone with a role in ensuring Wales provides world-class care and support to children with life-limiting conditions with exactly that; The raw data necessary to understand the basics of our community and allow us, in conjunction with other bodies, including the Welsh Government, to identify areas for improvement, investment and uplift in services to ensure that we are meeting the needs of every child with a life-limiting condition in Wales.

This study, conducted by the University of York has defined the cohort of babies, children and young people with a life-limiting condition in Wales, and provided data on their healthcare use, the medical complexity of their condition, the stage of the condition and deaths. This data will be invaluable in planning the next stages of our services in Wales.

This summary report presents the key data, and messages within this data, to provide a picture of the numbers and complexity of needs of babies, children and young people with life-limiting conditions in Wales. Those with an interest in the full data, the methodology and a deeper dive into the data should read the full report at [hopehouse.org.uk/trends-report](https://hopehouse.org.uk/trends-report)



## KEY FINDING 1: THE POPULATION OF CHILDREN WITH LIFE-LIMITING CONDITIONS INCREASED BY ALMOST A QUARTER IN THE DECADE FROM 2009-2019



### 3655 babies and children (under 18 years) with life-limiting conditions in Wales in 2019

- Increased overall by almost a quarter since 2009
- 58 in every 10000 children in Wales have a life-limiting condition (196 in every 10000 under 1 year olds)
- The largest proportional increases were seen in older age groups, likely indicative of increasing survival times

### 4289 babies, children and young people (under 26 years) with life-limiting conditions diagnosed in childhood in Wales in 2019

- Increased overall by almost a third since 2009

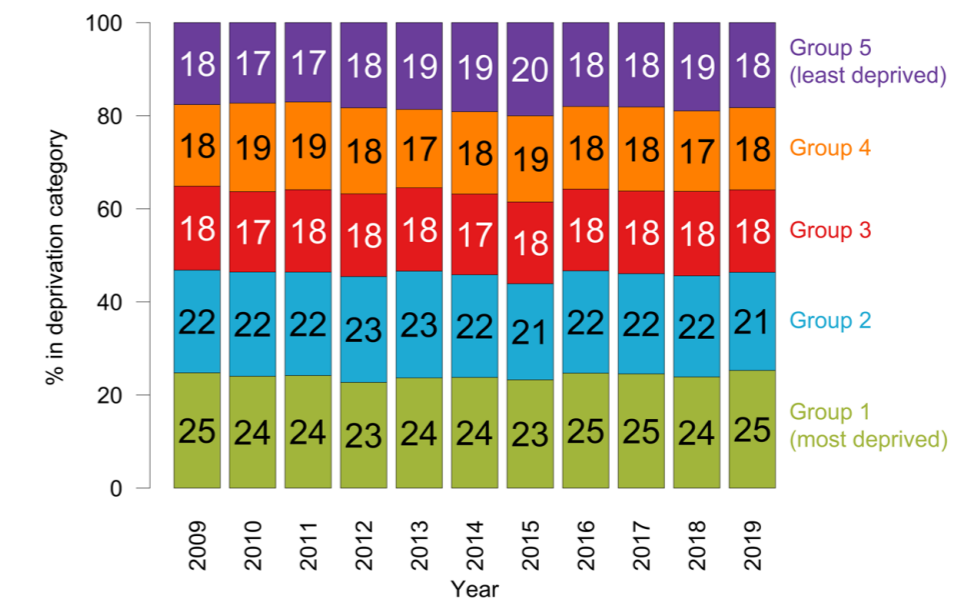
Life-limiting conditions were determined from diagnoses in hospital and General Practice records. Numbers presented for each year are the number of children or children and young people with a life-limiting condition recorded in that or a previous year and with an inpatient admission in that year while resident in Wales. Full lists of diagnoses and more details can be found in the full report. Prevalence was calculated as the number of children or children and young people per 10000 of the same age in the general population.

Figure 1: Prevalence of life-limiting conditions recorded in childhood among children and young people in Wales. Left: overall prevalence for children (under 18 years) and children and young people (under 26 years). Right: prevalence by age group. Figures adjacent to points are numbers of young people with life-limiting conditions.





## KEY FINDING 2: THERE ARE GEOGRAPHICAL DISPARITIES IN PREVALENCE OF LIFE-LIMITING CONDITIONS BETWEEN HEALTH BOARDS AND MORE CHILDREN AND YOUNG PEOPLE LIVING IN AREAS OF HIGHER DEPRIVATION THAN EXPECTED



**Prevalence of children with life-limiting conditions varies between Local Health Boards**

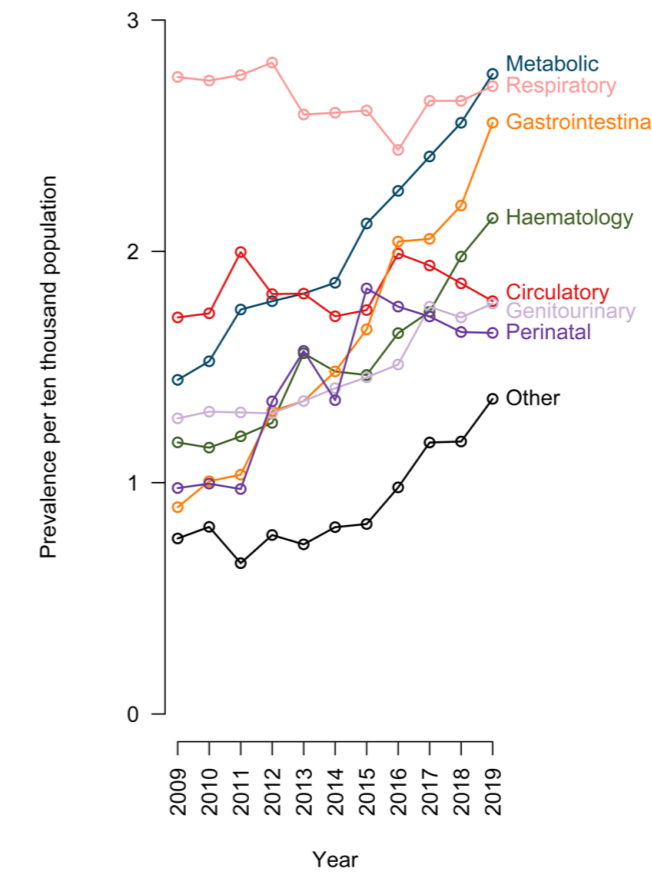
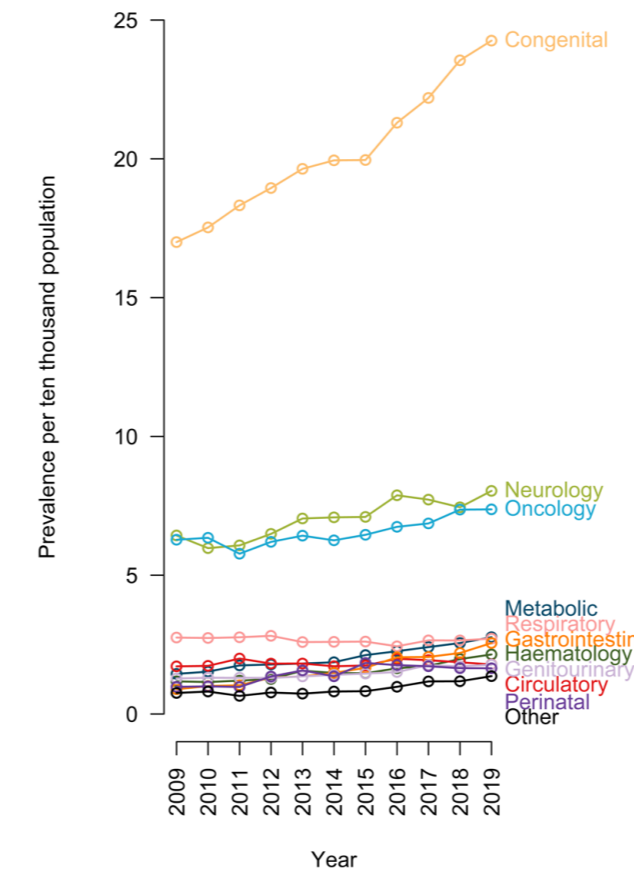
- Cwm Taf Morgannwg and Aneurin Bevan UHBs have higher prevalence

**THERE ARE HIGHER THAN EXPECTED NUMBERS WITH LIFE-LIMITING CONDITIONS IN AREAS OF GREATER DEPRIVATION - FOR EXAMPLE, THE MOST DEPRIVED 20% OF THE POPULATION CONTAINED 25% OF THOSE CHILDREN WITH LIFE-LIMITING CONDITIONS IN 2019**

*Distributions of prevalence of life-limiting conditions and proportion of LSOAs in the most deprived category across Local Health Boards. Local Health Boards: 1. Betsi Cadwaladr UHB; 2. Hywel Dda UHB; 3. Powys THB; 4. Swansea Bay UHB; 5. Cwm Taf Morgannwg UHB; 6. Aneurin Bevan UHB; 7. Cardiff and Vale UHB. Right, proportions of total number of children and young people with life-limiting conditions found in each deprivation category.*



### KEY FINDING 3: CONGENITAL CONDITIONS HAVE THE HIGHEST PREVALENCE, BUT THERE ARE MARKED INCREASES IN PREVALENCE IN MOST DIAGNOSTIC GROUPS



**Congenital abnormalities were the most common group of life-limiting conditions, with 24 per 10000 children and young people having a condition in this group in 2019**

- Neurology (8 per 10000) and oncology (7 per 10000) were the next biggest groups.

**Metabolic, gastrointestinal and haematology conditions saw the greatest proportional growth over time**

**Distributions of conditions were similar for children (under 18 years) and children and young people (under 26 years)**

Figure 3: Prevalence, for children and young people aged under 26 years, across the 11 categories of life-limiting condition (left) and detail of prevalence for conditions excluding the three most prevalent (right - excluding congenital, neurology and oncology).



## KEY FINDING 4: CHILDREN WITH LIFE-LIMITING CONDITIONS ARE DISPROPORTIONATELY HIGH USERS OF HEALTHCARE

1 in 172 children under 18 years have a life-limiting condition

- They were majority users of paediatric intensive care units (PICUs), accounting for 70% of PICU admissions and 73% of PICU bed days from 2009-2019
- They also had disproportionately high numbers of inpatient admissions, emergency inpatient admissions, Accident & Emergency Department visits and General Practice prescriptions.

### AMONG CHILDREN:

1 in 172 under 18 years have a life-threatening condition



### THEY ACCOUNT FOR (among children under 18):

7 in 10 paediatric intensive care bed days



2 in 10 hospital inpatient bed days



1 in 14 GP prescriptions



1 in 47 A&E visits

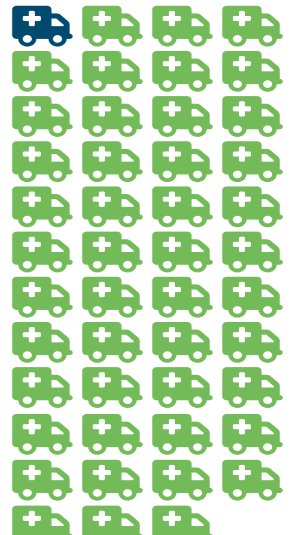
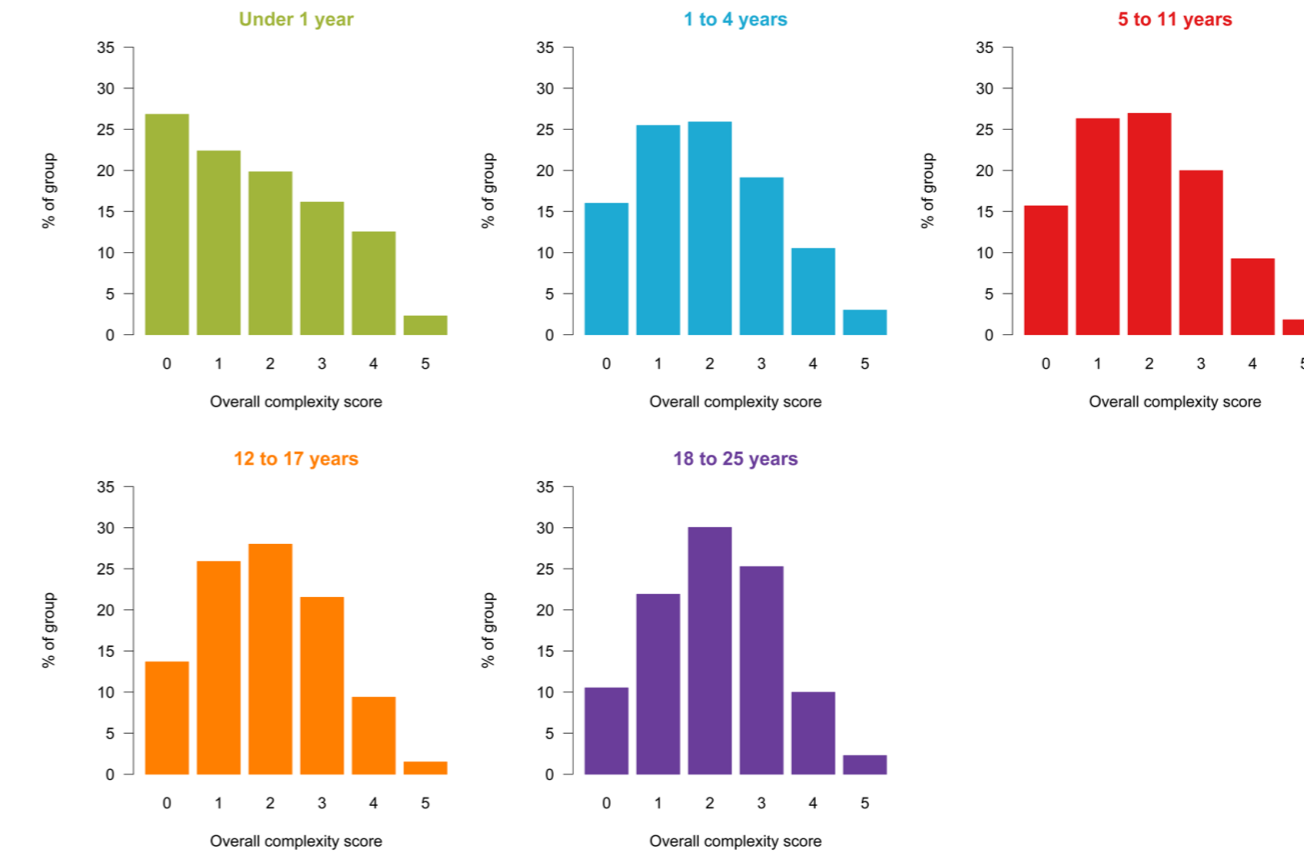


Figure 4: Summary of healthcare use for 2019, putting population size and healthcare use of children (under 18 years) with life-limiting conditions into context compared to all children.



## KEY FINDING 5: THERE IS A RANGE OF MEDICAL COMPLEXITY ACROSS CONDITIONS AND INCREASING COMPLEXITY WITH INCREASING AGE



All age groups, deprivation and condition categories have a spread of complexity scores

Complexity increases with increasing age

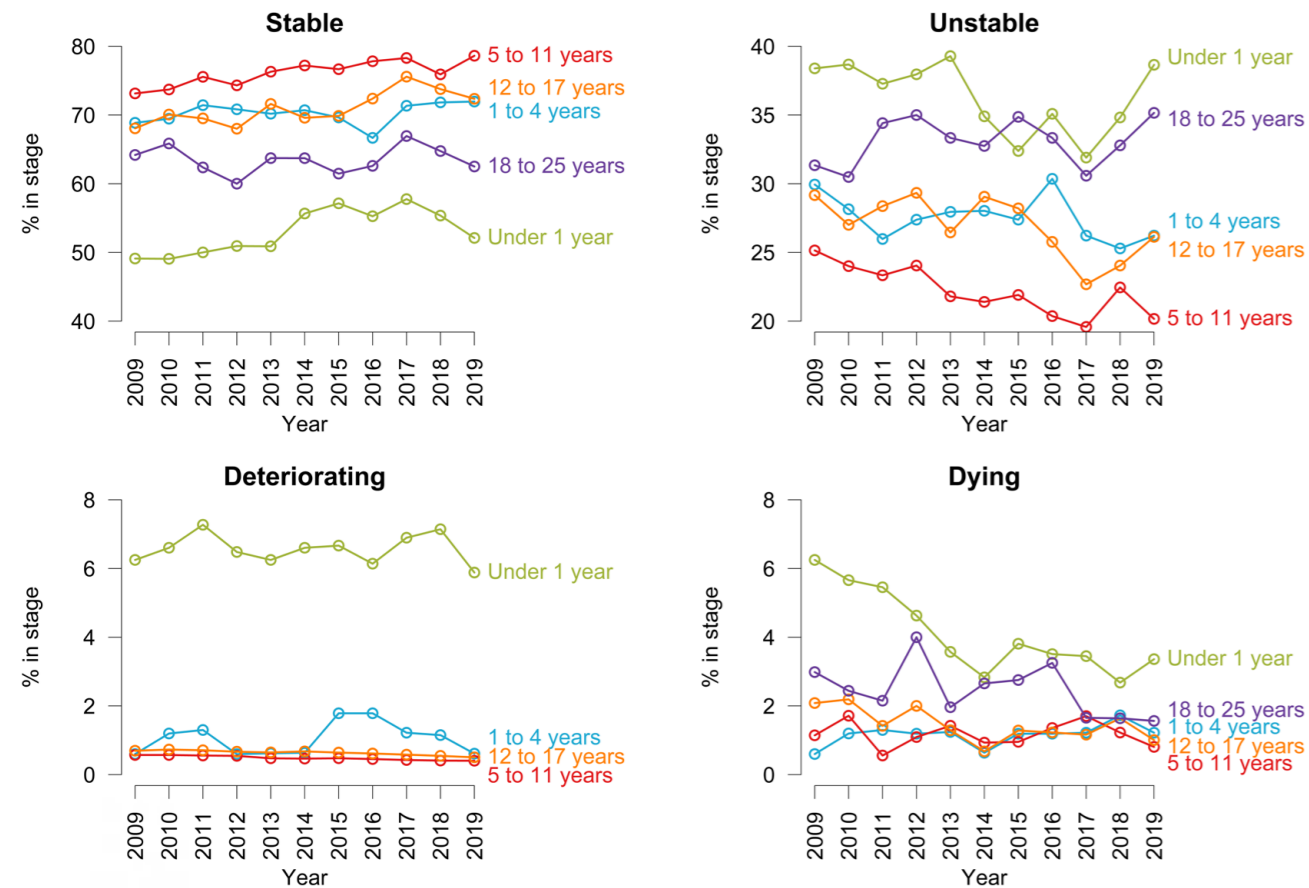
There has been a shift to higher complexity over time

- in 2009 44% of children and young people with a life-limiting condition had a complexity score of 0 or 1; 10% had a score of 4 or 5. In 2019 the corresponding proportions were 41% and 13%.

Figure 5: Overall complexity scores by age group for children and young people with a life-limiting condition diagnosed in childhood in Wales from 2009-2019.



## KEY FINDING 6: APPROXIMATELY A THIRD OF CHILDREN AND YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS IN WALES EXPERIENCE CLINICAL INSTABILITY EACH YEAR



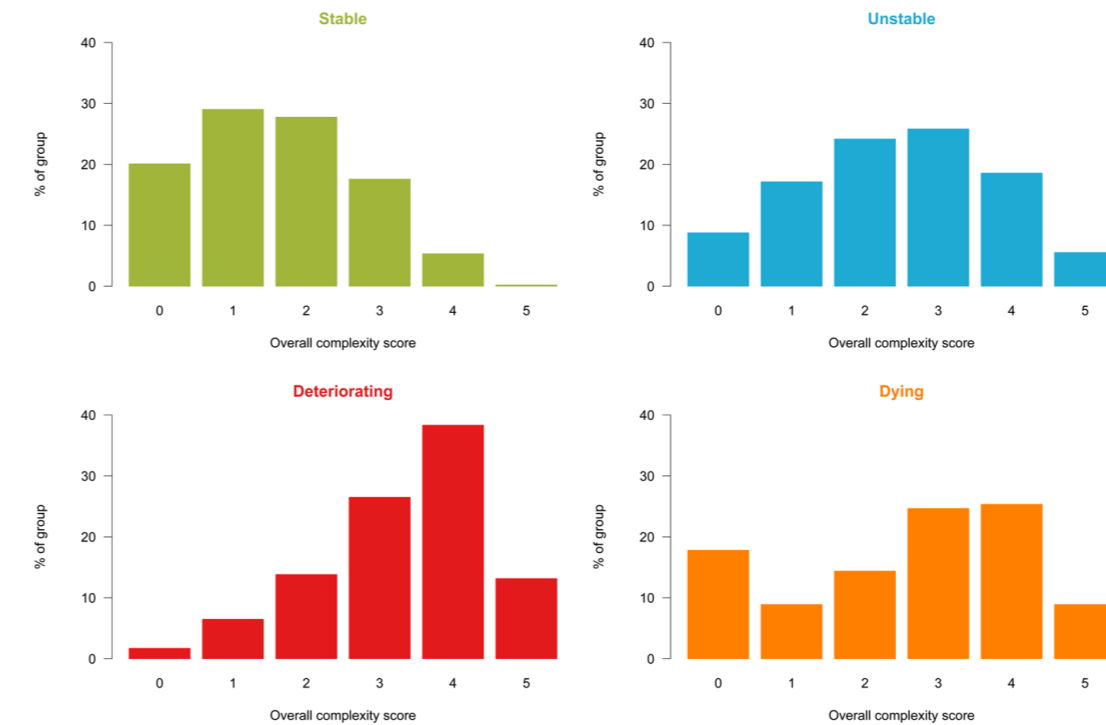
Each year around one third of young people with a life-limiting condition experience clinical instability

- 51% of those under 1 and 36% aged 18-25 years experienced clinical instability in 2019
- 5 to 11 year olds are the most stable (around 24% of this group experienced clinical instability in 2019)

Stage of condition was defined through healthcare events - an emergency hospital admission lasting two or more days indicated an unstable state; any emergency intensive care unit admission indicated a deteriorating state; the dying state was entered 28 days before death. Discharge to normal place of residence (with no death within 28 days) marked a return to a stable state.

Figure 6: Stage of condition, split by age group, for children and young people in Wales with life-limiting conditions diagnosed in childhood. The 18-25 years age group is omitted from the 'Deteriorating' graph due to a lack of data on intensive care unit admissions for this group.

## KEY FINDING 7: MEDICAL COMPLEXITY AND STAGE OF CONDITION ARE RELATED, BUT COMPLEXITY PROVIDES ADDITIONAL INFORMATION ON NEEDS



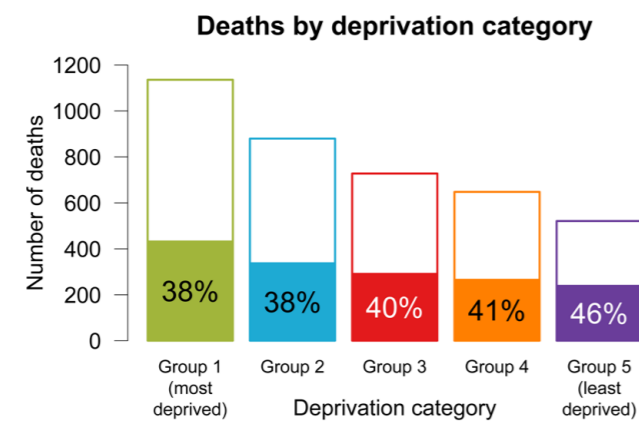
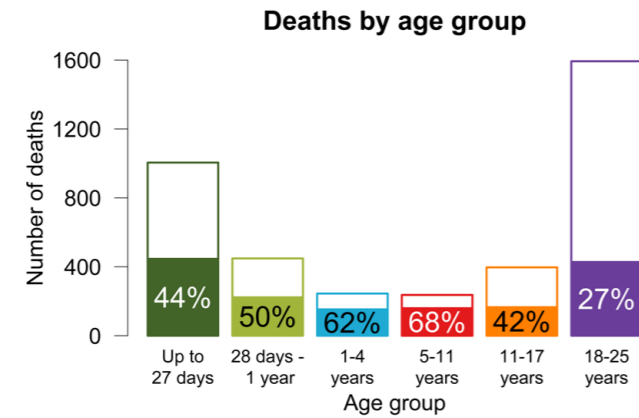
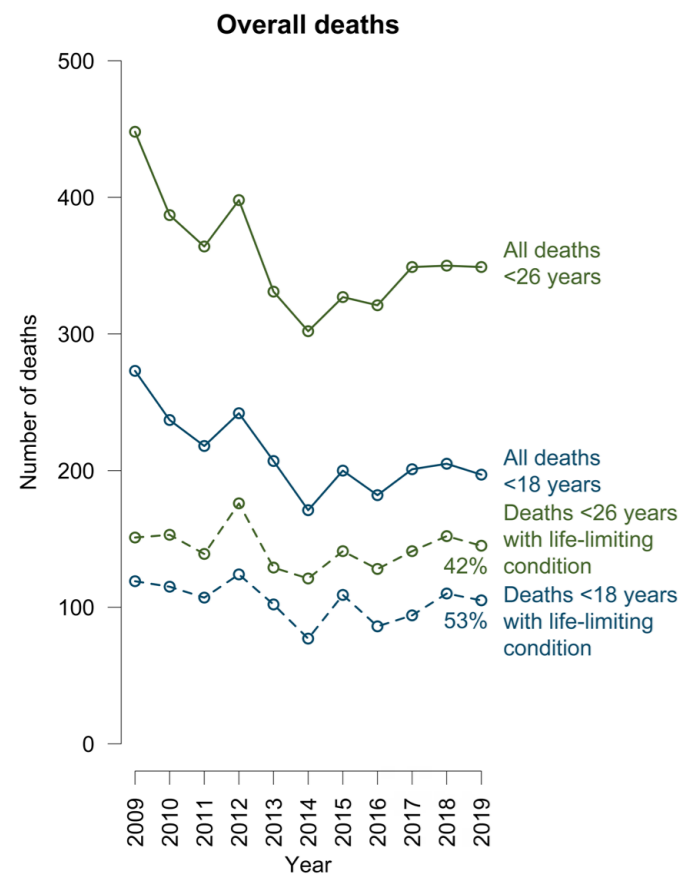
Complexity and stage of condition are related, but complexity scores provide additional information - there is a range of complexity scores within each stage of condition

There are few children and young people with life-limiting conditions who can be considered long-term stable or low complexity

Under 1s are a distinct group, for whom complexity measures may be limited - many under 1s who die have low complexity scores

Figure 7: Overall complexity scores, calculated yearly from 2009-2019 (except for those in the dying category, for whom the score is based on the last year of life) for children and young people with life-limiting conditions in Wales aged under 26 years and split by stage of condition in the year.

## KEY FINDING 8: MORE THAN HALF OF CHILDREN WHO DIE IN WALES HAVE AN UNDERLYING LIFE-LIMITING CONDITION



In 2019 104 children age 0-17 in Wales with a life-limiting condition sadly died

More than half of children who die in Wales have an underlying life-limiting condition

- In 2019, 53% of children (0-17 years) and 43% of children and young people (0-25 years) who died had an underlying life-limiting condition recorded
- From 2009-2019 these figures were 49% of children (0-17 years) and 40% of children and young people (0-25 years)
- This varied greatly by age with 44% percent in those under 1 year and 27% in those aged 18-25 years, with highest proportions in childhood: 1-4 years - 62%; 5-11 years - 68%

The largest actual number of deaths of those with life-limiting conditions occur in the under 1 year and 18-25 year age groups

Figure 8: Left: Deaths in Wales from 2009 to 2019 for children (under 18) and children and young people (under 26 years), with and without evidence of a life-limiting condition being present. Right: Deaths in Wales by age group (top) and deprivation category (bottom) with (shaded parts of bars) and without (unshaded parts of bars) a life-limiting condition being recorded as present. Overall bar height gives the total deaths in that group for 2009 to 2019. Percentages on bars are the proportion of deaths in each group that were for people with life-limiting conditions.



## SUMMARY AND IMPLICATIONS – A COMMENTARY FROM THE CHILDREN’S HOSPICES

**The data contained within this summary report shows that Wales is seeing an increase in the population of babies, children and young people with a life-limiting condition, and it is clear that this will have important implications for the future healthcare provision for children and young people living with these conditions in Wales.**

Data discussed in this document assesses numbers of children and young people with life-limiting conditions, their healthcare use, medical complexity, stage of condition and deaths. Some of the data shows an increase in the complexity of conditions of children with life-limiting conditions, that accompanied with this increase in overall numbers, mean that **babies, children and young people need additional services, and access to services for longer. The increase in prevalence places additional pressure on services, as increasing numbers of babies, children and young people with life-limiting conditions need care and support.**

### NUMBERS OF CHILDREN AND YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS

**The data showed variations by Local Health Board and deprivation category, with higher prevalence of life-limiting conditions in Cwm Taf Morgannwg and Aneurin Bevan UHBs** compared to others and disproportionately high numbers of children and young people with life-limiting conditions living in areas of higher deprivation. This shows that special consideration should be given to targeting resources to areas of higher need, including the most deprived areas.

Substantial increases in numbers were seen across most life-limiting conditions. Congenital and neurological conditions and cancers were most common, but the biggest increases were seen for metabolic, gastrointestinal and haematology conditions. Understanding the population and trends is essential for current and future service delivery and planning.

### HEALTHCARE USE

Babies, and children living with a life-limiting condition make up a small part of Wales’ population, this cohort has disproportionately high healthcare use.

Wales’ population of babies and children with life-limiting conditions account for a large number of hospital inpatient admissions, and inpatient bed days.

This data provides a starting point for discussions on how we design services to minimise unplanned hospital admissions and ensure those with life-limiting conditions in Wales receive the best possible support in the most appropriate setting.

Currently babies and children with life-limiting conditions are estimated to account for 1 in 14 GP prescriptions, however it is likely that the total number of prescriptions has been underestimated. There are likely to be a variety of reasons for this, including the fact that this data only looks at GP prescriptions, and does not take into account hospital given prescriptions.

### COMPLEXITY AND STAGE OF CONDITION

This scale has allowed for distinguishing of levels of complexity in an overall complex group. Having this breakdown of complexity will allow us to develop and deliver better person centred services that best meet the needs of babies, children and young people with life-limiting conditions.

**What is also clear from the data is that all condition groups show a wide spread of complexities**, with no particular condition group standing out as having less or more complex cases than any other group. It is also clear that, those with life-limiting conditions in Wales are living longer, overall complexity has shifted towards the ‘more complex’ end of the scale. What this means for children’s palliative care providers in Wales is that children with

life-limiting conditions are more likely to have more complex needs than 10 years ago.

The research team also looked at stage of condition. To do this, the team looked at four stages of condition, stable, unstable, deteriorating and dying. Transition between these four stages was assessed using a model that looked at transitions within a medical setting to assess the stage of condition.

While approximately a third of young people with life-limiting conditions experienced instability in each year, it is worth noting this was not the same group in each year. **Stable groups cannot be discounted when planning for future service need, rather it is this group – those with the potential to become unstable – who should be considered most when planning for future services.**

**It is also clear from the data that young adults (those in the 18-25 age group) have higher complexity, and therefore will likely have additional needs that will not be met by traditional adult services.** It is incredibly vital that transitions between child and adult services are looked at to ensure that services for those reaching adulthood are appropriate for the needs of the person, and that those delivering their care, and who know them best, can be fully involved in decision making and care.

Amongst those who are in the three non-stable groups, there is a higher level of complexity, and concurrently, those in the more complex groups are less likely to be stable amplifying the care needs for this most vulnerable

group. However, this relationship is less clear among those who died. The study found that this was due to many of those who died aged under 1 year (a substantial proportion of total deaths) having low complexity scores. This suggests that the complexity score is less good at determining stage of condition in children aged under 1 year than in other age groups. We must recognise that very young children represent a different group with more uncertain outcomes and less easily quantified complexity, compared to older children.

### DEATHS

The final series of data looked at by the team looked at deaths of children and young people with life-limiting conditions.

Proportions of deaths that had evidence of a life-limiting condition varied between age groups, lowest in those who died before 28 days and those who died over 18 years and highest in deaths in childhood (e.g. 62% of deaths in children aged 1 to 4 years and 68% of deaths from 5-11 years had a life-limiting condition present). The relatively lower proportion of deaths in the under 1s underlines the difficulty in predicting trajectories in this group and the variations between severity under broad diagnoses.

**Numbers of deaths, with and without evidence of an underlying life-limiting condition were disproportionately higher in more deprived areas**

**compared to the number of children and young people in each category.**

Higher numbers of children with underlying life-limiting conditions died in the more deprived areas. However, in less deprived areas a greater proportion of child deaths had evidence of a life-limiting condition compared to more deprived areas. We know that health inequalities disproportionately affect those in the most deprived groups, the deaths data collected by the research team is interesting, and poses specific policy challenges that will need further investigation as this data is taken forward.





## NEXT STEPS

**THIS RESEARCH PROVIDES, FOR THE FIRST TIME, DETAILED AND ROBUST DATA ON THE NUMBERS AND COMPLEXITY OF CHILDREN AND YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS IN WALES. TAKEN TOGETHER WITH THE LIVED EXPERIENCES OF CHILDREN AND FAMILIES IT PROVIDES A SOUND AND COMPELLING BASIS FOR THE DEVELOPMENT OF CHILDREN'S PALLIATIVE AND END OF LIFE CARE POLICY AND SERVICES.**

**IT IS HOPED THAT ALL PARTIES AND STAKEHOLDERS WITH INTEREST, RESPONSIBILITY, AND INFLUENCE IN CHILDREN'S PALLIATIVE CARE IN WALES WILL WORK TOGETHER TO SHAPE AND DELIVER, WORLD-CLASS, SUSTAINABLE SERVICES TO MEET THE NEEDS OF THE 4289 CHILDREN AND YOUNG PEOPLE LIVING IN WALES WITH LIFE-LIMITING CONDITIONS.**

hope house tŷ gobaith  
children's hospices



GIG  
CYMRU  
NHS  
WALES

Rhaglen Genedlaethol Gofal  
Lliniarol a Diwedd Oes  
National Palliative and End  
of Life Care Programme



Tŷ Hafan

CHILDREN'S HOSPICE  
HOSBIS I BLANT



The full report can be downloaded at [hopehouse.org.uk/trends-report](https://hopehouse.org.uk/trends-report)

