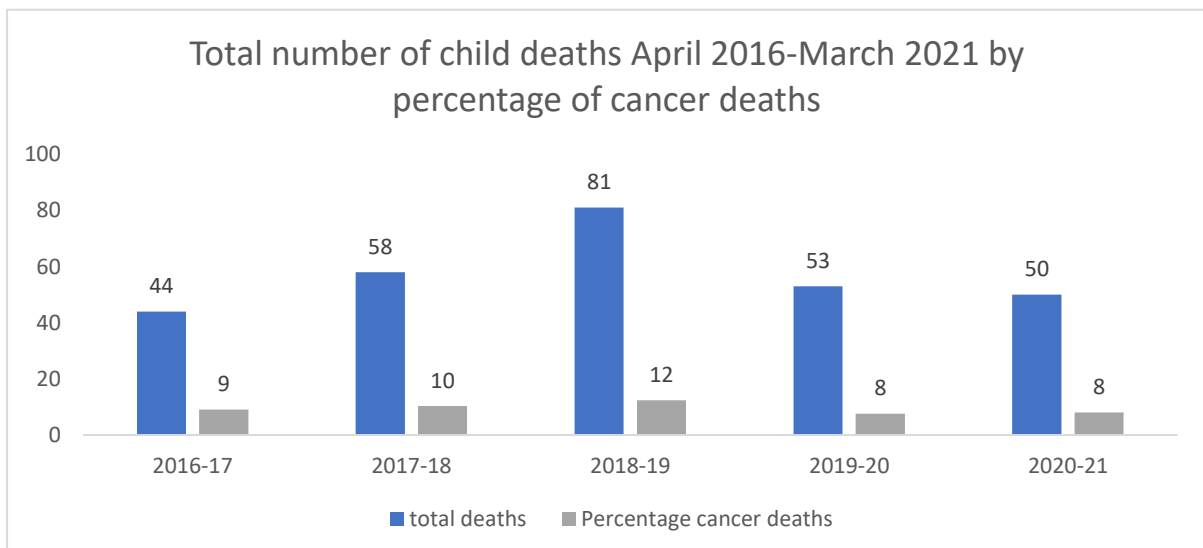


Surrey CDOP Review of Child Deaths from Cancer 2016-2021

During April 2016 to the end of March 2021, 35 deaths were reported to Surrey Child Death Overview Panel (CDOP) of children who were resident in Surrey and died from cancer. As shown in Figure 1 below, these deaths account for a stable percentage of all child deaths in Surrey of between 8 – 12%.

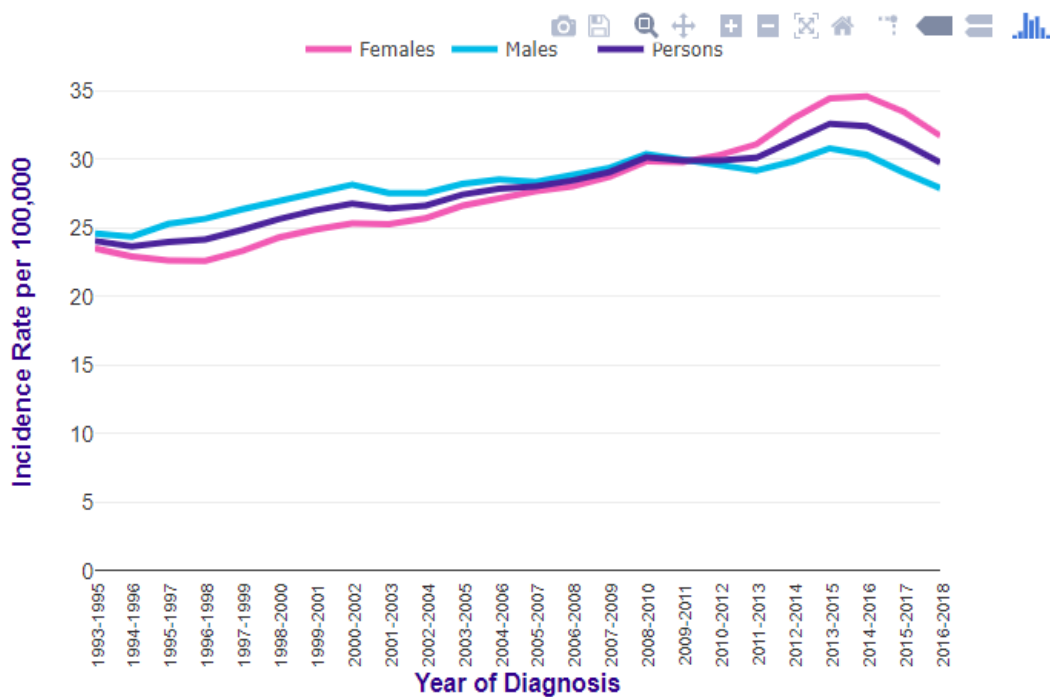
Figure 1



Around 4,400 children and young people are reported to be diagnosed with cancer every year in the UK¹. Cancer Research UK² estimates that around 8 out of 10 of those diagnosed with cancer survive for at least 10 years, many will be considered to be cured. Hodgkin Lymphoma and retinoblastoma (most commonly identified under 5 years) are curable in more than 95% of cases. During the 1960's about 2-3 out of 10 were successfully treated³ which represents a 69% reduction since the 1970's⁴.

Figure 2

Young People's Cancers (C00-C97, D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5), European Age-Standardised Incidence Rates, Ages 15-24, UK, 1993 to 2018



Despite cancer not being considered common in children, it is the leading cause of death from illness for children between the ages of 1-15 and whilst the numbers of children dying from differing types of cancer has reduced, the amount of childhood deaths from cancer

¹ [Cancer Research UK for Children & Young People](#)

² [What is children's cancer? | Cancer Research UK](#)

³ [What is children's cancer? | Cancer Research UK](#)

⁴ [Children's cancers mortality statistics | Cancer Research UK](#)

overall has increased⁵. The increase in incidence since the 1990's is approximately 12%⁶ as shown above in Figure 3⁷. There were 236 reported deaths from cancer in children between 2015-2017, which was reported to be representative of 23% in all deaths in children during 2017.

There are approximately 1,838 new cases of children's cancer diagnosed each year in the UK which accounts for less than 1% of the total cases within the UK. The peak rate of children's cancer identification in the UK is between 0-4 years of age.

Cancer Research UK⁸ list the most common types of childhood cancer as:

- Acute leukaemia's
- Cancer of the brain and spinal cord

Other types include:

- Lymphoma
- Muscle or bone cancer (rhabdomyosarcoma, osteosarcoma and Ewing's sarcoma)
- Neuroblastoma
- Wilm's Tumours
- Retinoblastoma

Following a change to the National Statutory Guidance for Child Death Review⁹, all deaths including those anticipated to occur within the 24 hours preceding the death are now required to have a Child Death Review Meeting. This change in guidance relates to any child death occurring after 29th September 2019. The guidance states that "the nature of this meeting will vary according to the circumstances of the child's death and the practitioners involved. It would, for example, take the form of a case discussion following a Joint Agency Response, a perinatal mortality review group meeting in the case of a baby who dies in a

⁵ [What is children's cancer? | Cancer Research UK](#)

⁶ [Children's cancers incidence statistics | Cancer Research UK](#)

⁷ [Children's cancers incidence statistics | Cancer Research UK](#)

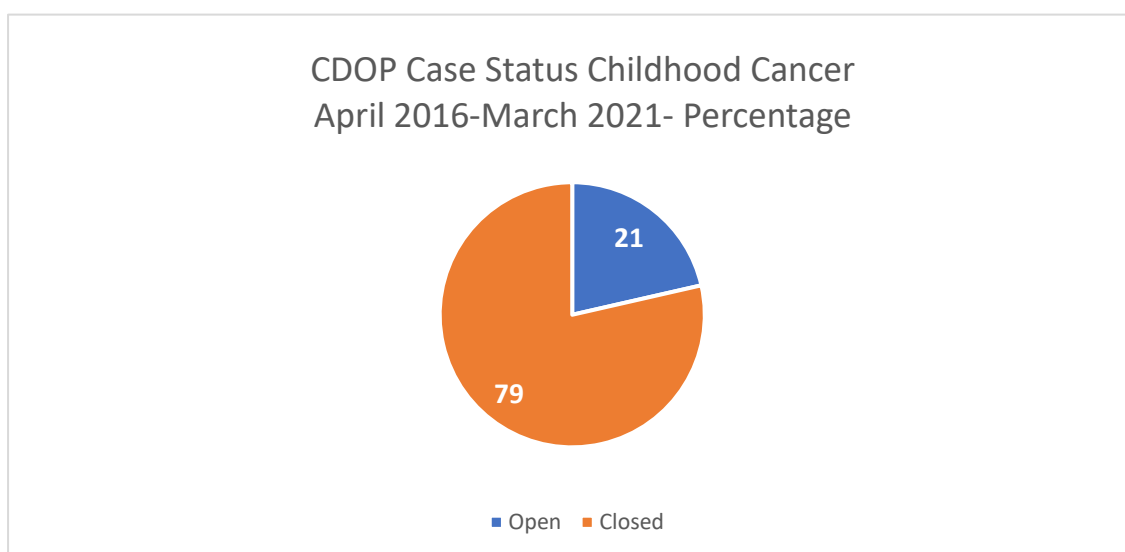
⁸ [What is children's cancer? | Cancer Research UK](#)

⁹ [Child Death Review Statutory and Operational Guidance \(England\) \(publishing.service.gov.uk\) \(p.15\)](#)

neonatal unit, or a hospital-based mortality meeting following the death of a child in a paediatric intensive care unit”. Within Surrey, an agreement has been made with Shooting Star Hospice and The Royal Marsden Hospital that a regular, joint review would occur. This will primarily be led by The Royal Marsden Hospital, as the vast majority of cases occur under the care of their service. Should any significant difficulties, safeguarding concerns or parental concerns be identified during the information gathering stage, an independent Child Death Review Meeting will be convened by the Surrey Child Death Review Team to ensure there is no conflict of interest when identifying learning.

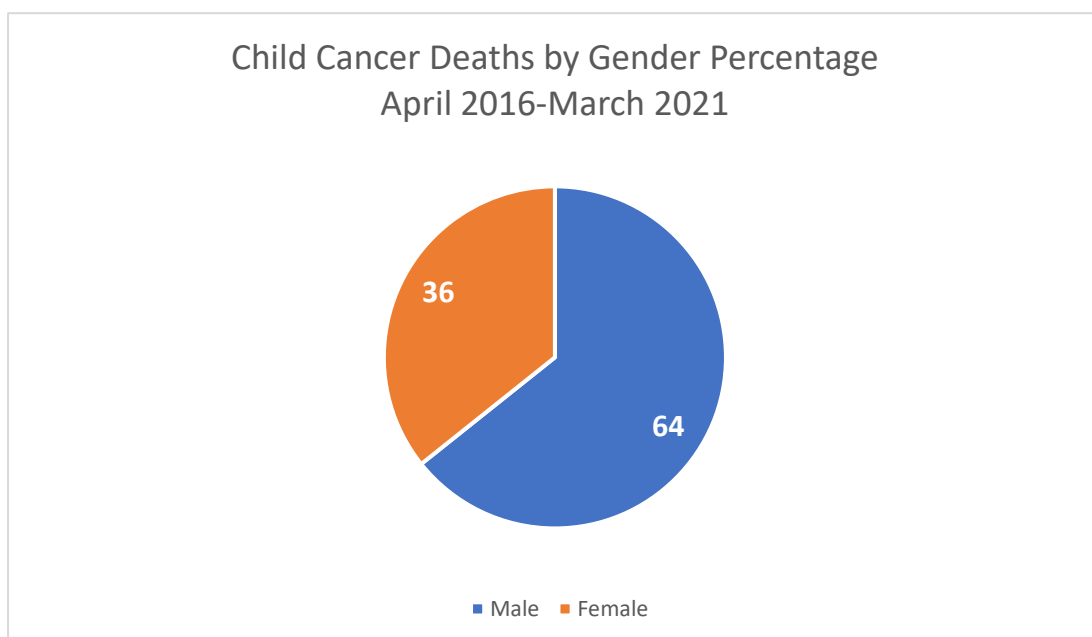
At the time of writing this report, 79% of all cancer related cases reported to Surrey CDOP were completed and closed as shown in Figure 3 below. A further 21 % of cases remain open awaiting the review process or for closure at the CDOP Panel to be held in October 2021. As the majority of child cancer deaths can have a Medical Certificate for Cause of Death (MCCD) completed at time of death, they do not require a Coronial Post Mortem and investigation. These cases are also extremely unlikely to trigger a Joint Agency Response or be subject to a Local Child Safeguarding Practice Review. Therefore the cases represented within this report do not remain open to Surrey CDOP for the same length of time as an unexpected child death.

Figure 3



As outlined within Figure 4 below, the majority of deaths were male, which indicates that survival rates from cancer are higher for girls, as data from Cancer Research UK demonstrates a higher number of girls are diagnosed each year. A higher incidence of male mortality is in line with the National data¹⁰; 44% of deaths were female and 56% male. The higher incidence of male deaths is also captured within the Surrey Child Death Review Annual Report.

Figure 4



A significantly higher proportion of the child deaths from cancer sit within 5-14 years as outlined in Figure 5 below. This trend is not unexpected and is similarly found in previous reporting from Surrey CDOP.

¹⁰ [Children's cancers mortality statistics | Cancer Research UK](#)

Figure 5

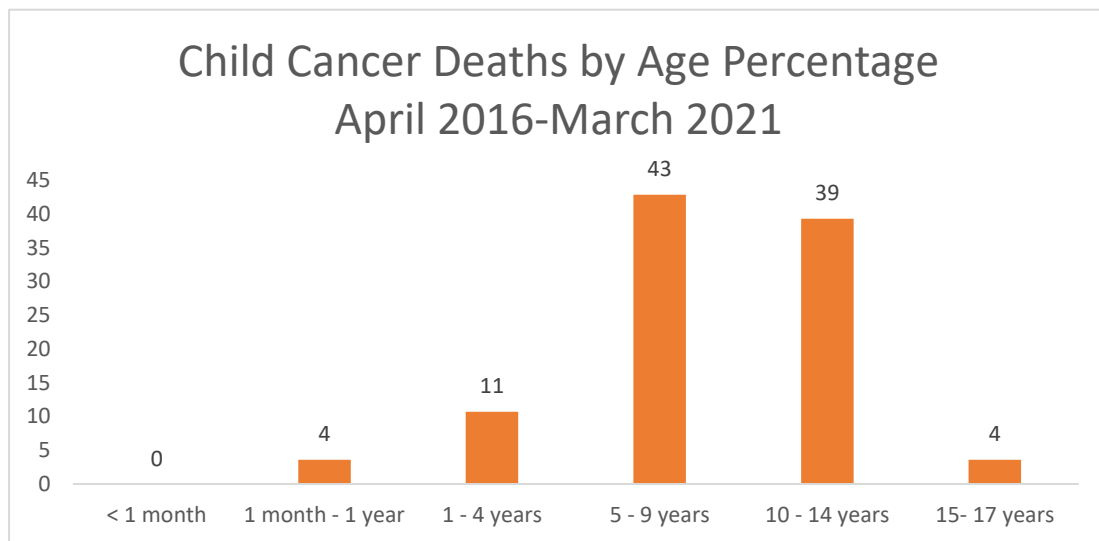


Figure 6

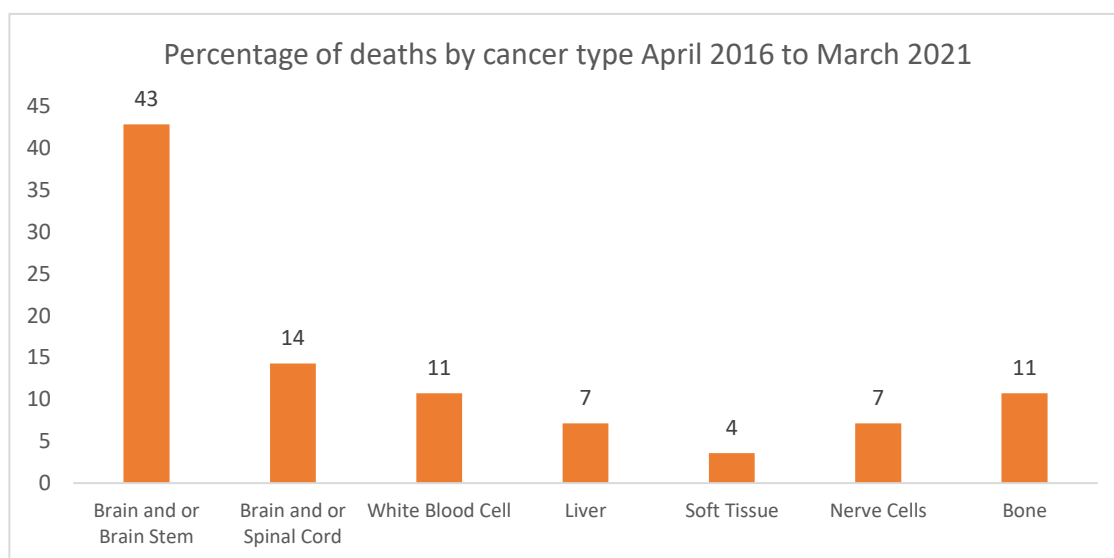


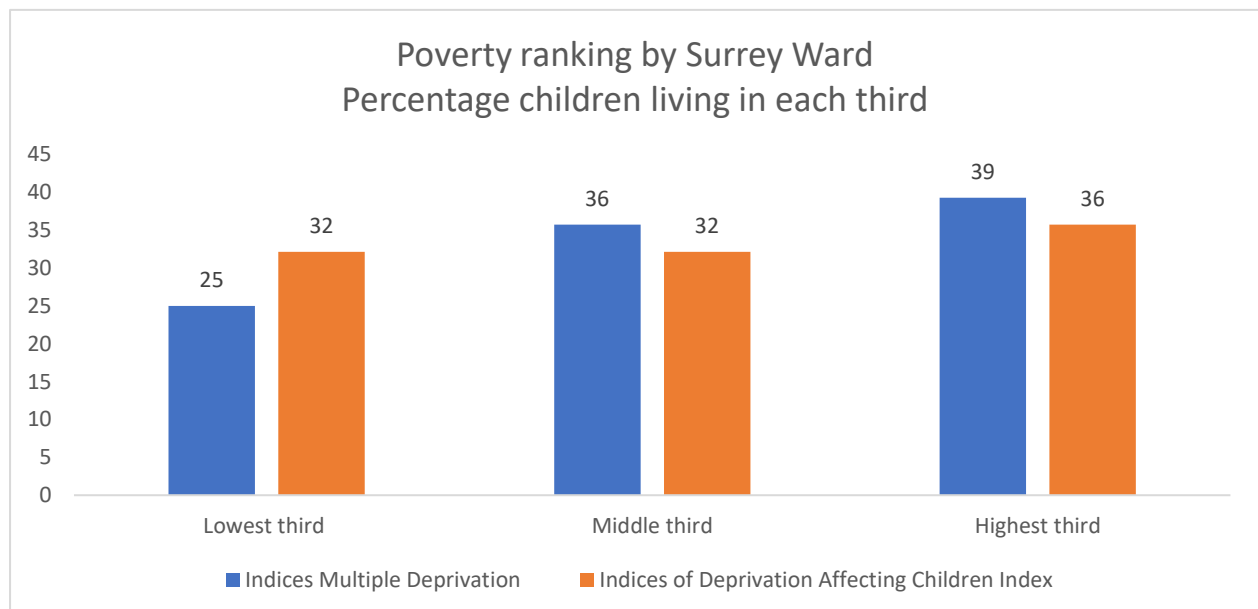
Figure 6 (above) shows that the majority of cancer deaths within Surrey are relating to the brain, brain stem or spinal cord. Cancer Research UK states that brain tumours are relatively rare and less common in children than adults¹¹. It is reported that they are the second most common type of childhood cancer with around 410 children diagnosed each year in the UK. There is no evidence to link brain tumours with pregnancy or early

¹¹ [About childhood brain tumours | Cancer Research UK |](#)

childhood. It is increasingly difficult to control a recurrent or relapsed tumours. Whether death is caused by a relapse is not currently a specific part of the data collection within Surrey CDOP so it would be recommended that this information be specifically gathered as part of the process for future deaths.

Figure 7 below, highlights the poverty ranking by Surrey ward. This shows a fairly even spread across all thirds, suggesting that poverty does not have any direct impact on death from childhood cancer.

Figure 7



It was of note, however, that 4 of the 28 children considered at CDOP and closed, lived in lower super output areas (LSOA, explained below) that fall within the lowest 50% in England for health deprivation and disability and that 5 of the 28 children lived in a LSOA ranked in the lowest 50% in England for Indices of multiple deprivation.¹²

¹² Figures taken from 2019 Indices of Deprivation: [English indices of deprivation 2019 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019)

LSOA's are a geographic hierarchy designed to improve the reporting of small area statistics in England and Wales. An LSOA will have an average population of 1500 people or 650 households. The Health Deprivation and Disability Domain measures the risk of premature death and the impairment of quality of life through poor physical or mental health. The domain measures morbidity, disability and premature mortality but not aspects of behaviour or environment that may be predictive of future health deprivation.

The Index of Multiple Deprivation (IMD) combines information from the following domains:

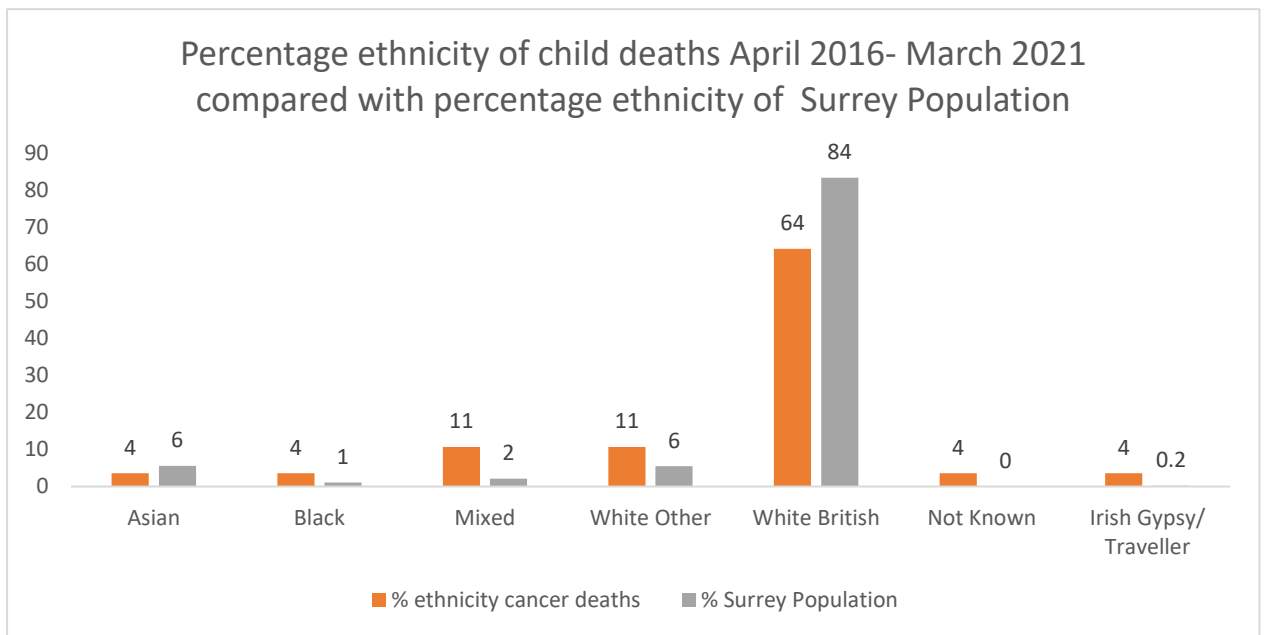
- Income Deprivation,
- Education, Skills and Training Deprivation
- Employment Deprivation
- Health Deprivation and Disability
- Crime
- Barriers to Housing and Services
- Living Environment Deprivation

The domains are weighted and are used to produce an overall relative measure of deprivation.

Figure 8 (below) shows a relatively even spread of deaths amongst children of Asian, Black, Mixed, White Other and Irish Gypsy/Traveller ethnicity. A significant number of children are of White British ethnicity which is congruent with the general demographic of Surrey which accounts for 83.5% of the total population¹³.

¹³ [Ethnicity – Surrey-i \(surreyi.gov.uk\)](https://www.surreyi.gov.uk/ethnicity)

Figure 8



During the CDOP meeting, many factors are considered. The final section of this paper will examine the findings of the cases reviewed and closed at CDOP during the years 2016-2021, which as discussed previously, accounts for 79% of the cases considered within this review. It was noted that for 4% of the death, ethnicity was not captured. It is recommended that data gathering for ethnicity be improved for future reviews.

Figure 9 below shows that the majority of cases were not known to Children’s Services, but for 18% of the cases, this data was unknown. It would be recommended that during future reviews, this data is collected routinely. Within the necessity for all expected deaths to have a Child Death Review Meeting since October 2019, it is anticipated that the substantial number of ‘not known’ outcomes will reduce.

Figure 9

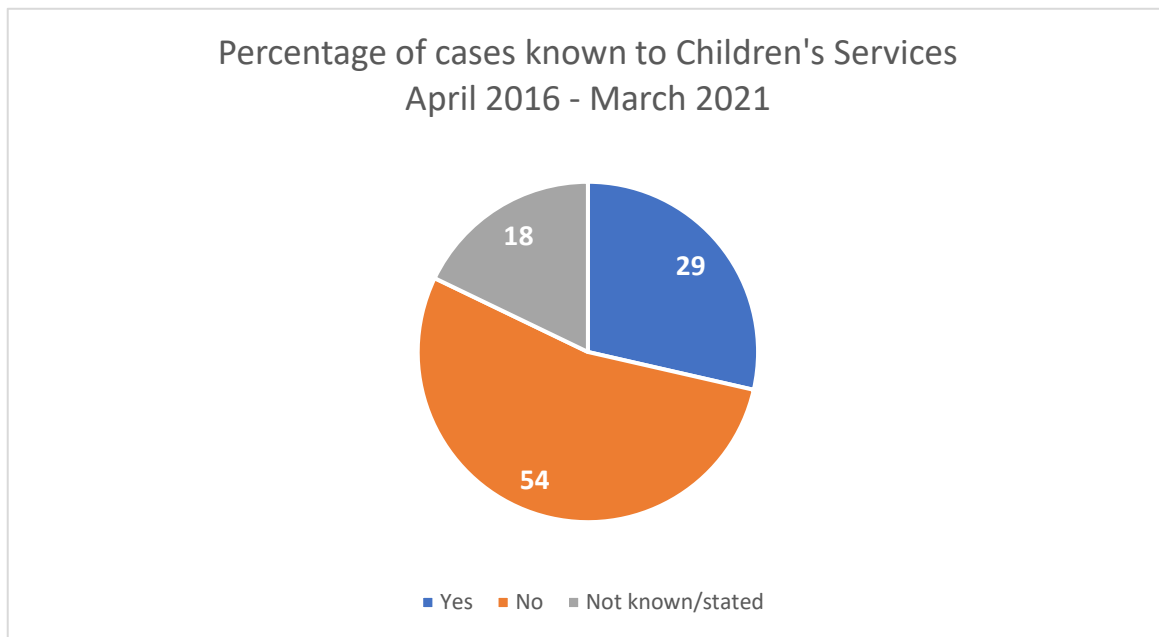
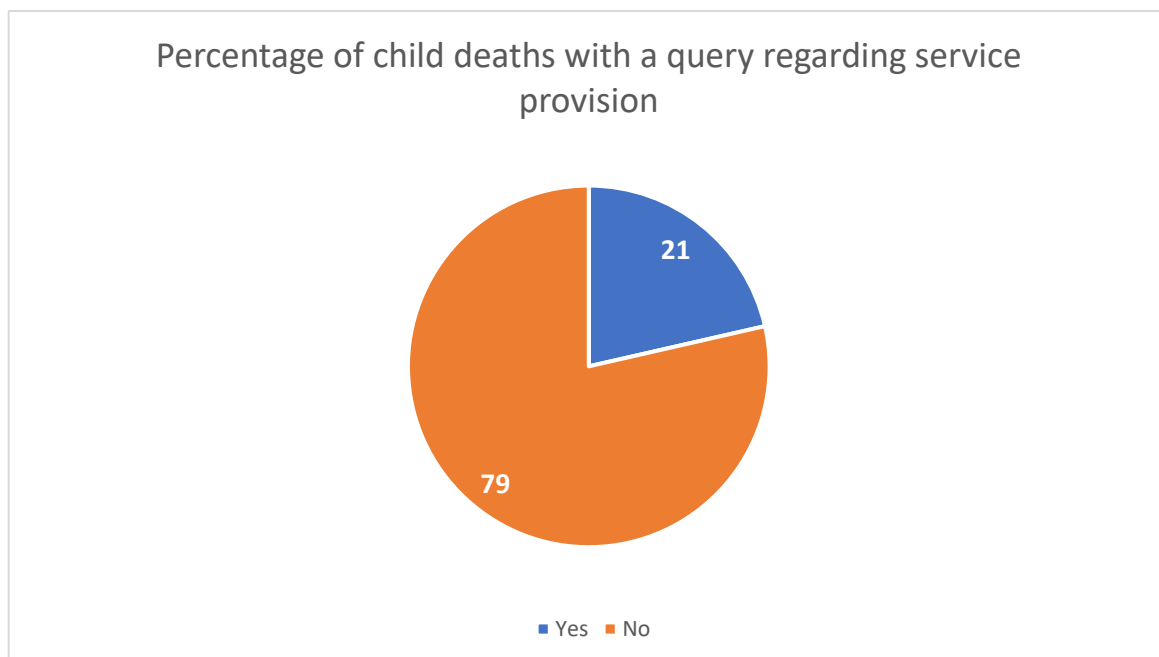


Figure 10



79% percent of cases reviewed by Surrey CDOP did not have any queries raised regarding the service provision when caring for a child with cancer (Figure 10 above), however 21% of cases did identify issues with service provision. Examples of the issues raised include prognosis not communicated with family, slow speed of referral to tertiary centre,

disagreements with treatment when parents were seeking opinion outside the UK, language barriers that were not sufficiently overcome, disagreement with parents about course of treatment and a tertiary centre fax machine that was reported to have lost a referral for medication.

Following each review, learning was identified in 64% of cases as shown in Figure 11 below. Once identified, learning is routinely disseminated across the Surrey provider networks either on an individual provider basis as required, via the CDOP Bulletin or more recently via the Surrey CDOP e-newsletter. 18% of the reviews are noted in Figure 11 are still outstanding and are due to be closed either at the November 2021 Themed CDOP meeting or at a later date depending on review progress and date of death. The learning captured during the CDOP process matches exactly with the issues identified in service provision as outlined by Figure 10 above.

Figure 11

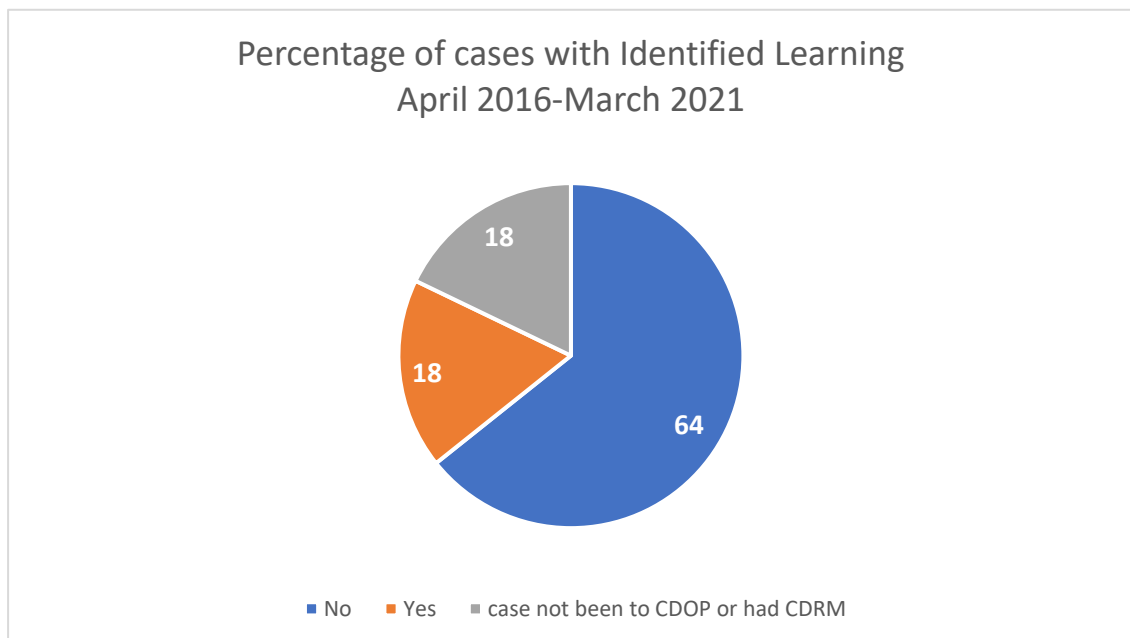


Figure 12 (below) outlines whether there was any delay identified by Surrey CDOP when professionals were initially in the process of diagnosing the cancer. For 46% of cases, it was decided by Surrey CDOP that there was no delay identified. However, for 43% of cases it was felt that there was not enough information to make an informed decision as to whether there was or was not a delay in the diagnosis. With the Child Death Review Meetings occurring for all cases since late 2019 and all future cases, it is anticipated that this data collection will improve significantly. Consideration of a delayed diagnosis now forms part of the new criteria when considering the care of a child with a diagnosis of cancer both on eCDOP and within the Child Death Review Meeting.

When considering whether there was a delay in diagnosis, the NHS Constitution states that each patient has a right to be seen by a cancer specialist within a maximum of two weeks from GP referral where cancer is suspected¹⁴. This data is collected by all NHS trusts and should be available to clinicians at the child death review. The cancer wait time (2-week rule) operational standard is 93%, in 2017-18 1.94 million referrals were made by primary care clinicians. This is an increase of 94% since 2010-11¹⁵. In 2020-2021, 235,549 patients were outside the 93% operational standard for the two-week referral¹⁶. Clinicians at the child death review would decide if a referral delay had a significant impact on a child's death.

A further point to be considered going forward would be the identification of whether the child had any interruption in treatment plans due to disruption in cancer service delivery as a consequence of the Covid Pandemic. It is estimated that 22% of patients had a disruption in treatment due to COVID 19¹⁷.

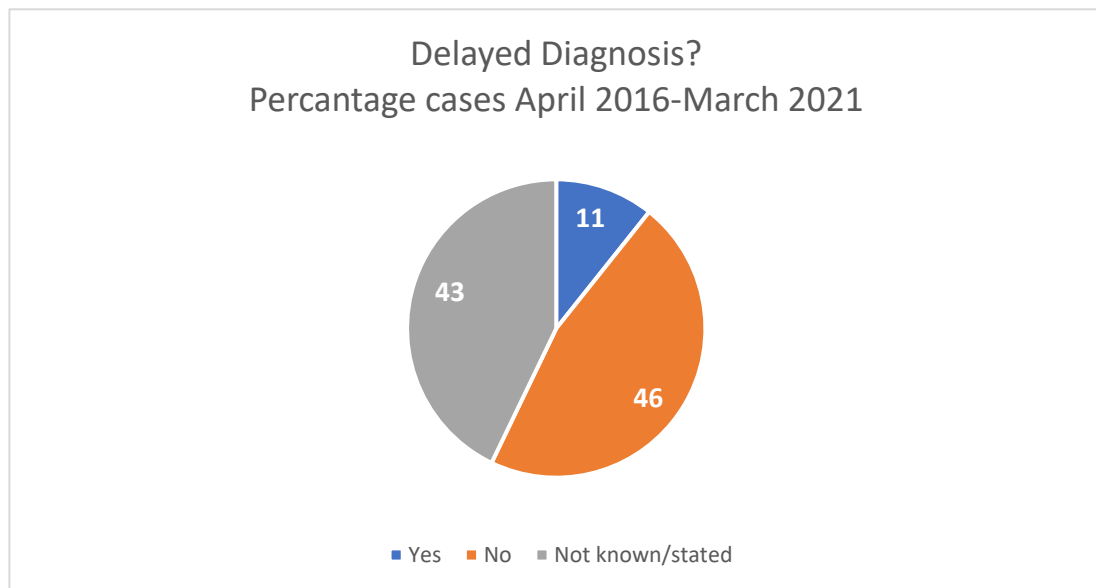
¹⁴ Delivering cancer wait times 2015 <https://www.england.nhs.uk/wp-content/uploads/2015/03/delivering-cancer-wait-times.pdf>

¹⁵ NHS waiting time for elective and cancer treatment 2019 www.nao.org.uk/wp-content/uploads/2019/03/NHS-waiting-times-for-elective-and-cancer-treatment-Summary.pdf

¹⁶ Cancer wait times National time series 2021 <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>

¹⁷ The forgotten 'C' The impact of COVID on cancer care 2020 [The Forgotten 'C'? The impact of COVID-19 on cancer care \(macmillan.org.uk\)](http://TheForgotten'C'?TheimpactofCOVID-19oncancer.care(macmillan.org.uk))

Figure 12



The final 2 Figures (13 &14) highlight the most important factors when considering the final elements of family care. The last wishes and days a family is able to spend with their child are of the highest importance and these memories are the ones families will hold on to for the rest of their lives. It is vital we meet their wishes in any way possible. It is important to plan for both the child and family when there is no further medical intervention available, to ensure dignity and compassion throughout. It is highly likely a family are going to be of heightened sensitivity during the final weeks and days, so any actual or perceived threats to meeting their final wishes will be devastating. There are many reasons a family cannot have their final wishes such as disease progression, medical intervention and availability, however we must as a Surrey wide community of professionals ensure that families final wishes are never stopped due to bureaucracy and paperwork.

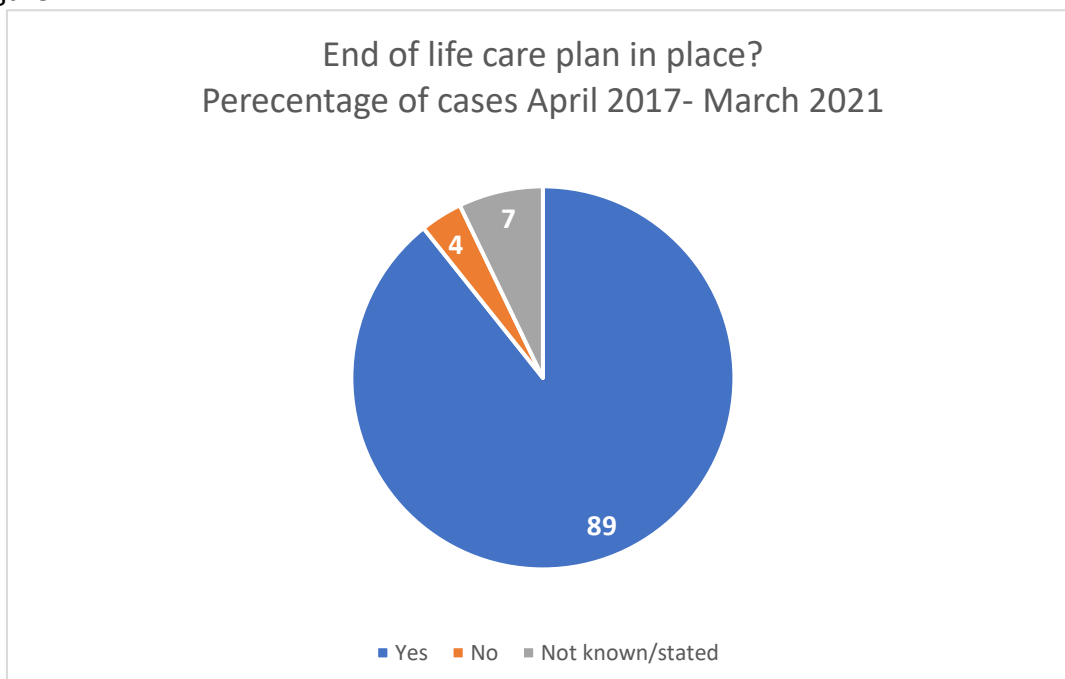
There is often a way around paperwork and policy¹⁸, and it is at these times that it becomes of most importance to ensure families are supported with trauma informed care. There is no greater tragedy that watching your child die, so it is crucial we get the care right and do not allow small, administrative issues stand in the way of delivering high quality care.

¹⁸ [Busting bureaucracy: empowering frontline staff by reducing excess bureaucracy in the health and care system in England - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/busting-bureaucracy-empowering-frontline-staff-by-reducing-excess-bureaucracy-in-the-health-and-care-system-in-england)

One of the best evidence-based ways we can support families during their final weeks is with the creation of a care plan. NICE Guidelines are clear and helpful to ensure there are plans in place. They state that it is paramount to “recognise that children and young people with life-limiting conditions and their parents or carers have a central role in decision-making and care planning,” and “when developing plans for the care of the child or the young person with a life-limiting condition, use parallel planning to take account of possible unpredictability in the course of the condition (p.5)”¹⁹

Figure 12 below, evidence suggest that for the majority of cancer deaths in Surrey an end-of-life care plan is in place. For 7% of the cases, Surrey CDOP were unable to identify whether this had occurred. For future reporting we expect this to be 100% known as all children who die after late 2019 will now have a Child Death Review Meeting where this information will be routinely captured. It was not possible for the 4% who did not have an end-of-life care plan to ascertain whether there was any significant reason for this as the cases were historical and closed at CDOP several years earlier.

Figure 12



¹⁹ [End of life care for infants, children and young people with life-limiting conditions: planning and management \(nice.org.uk\)](https://www.nice.org.uk/guidance/NG101)

Figure 13

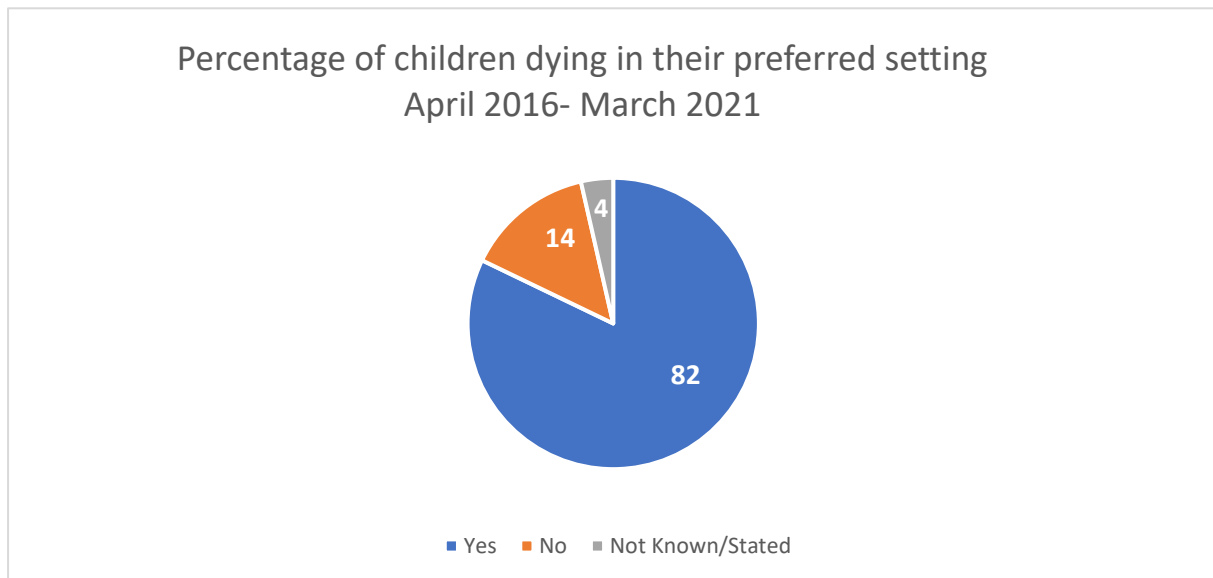


Figure 13 above, shows how many children were reported to have died in their preferred setting. Again the 4% of unknown answers should not appear in future reporting as this is also routinely captured during a Child Death Review Meeting.

For a selection of the 14% for whom the answer was no, the following reasons stated were

- Prognosis not communicated with family so planning could not take place
- Hospice paperwork delayed transfer to hospice both pre and post death
- Child was too unwell for transfer
- No reason identified

Whilst reasons such as a child being too unwell for transfer are understandable, it raises the question with the benefit of hindsight bias as to whether earlier conversations and planning may have facilitated the move earlier. For the cases where no reason was identified it raises the importance of asking why at point of identification. As with previous points, it is expected that with an individual Child Death Review Meeting this data capture should improve without any intervention. It is sad to identify that paperwork or communication were a barrier for parent's final wishes and as identified earlier within the earlier section, there is often a way around if professionals work together.

Future Recommendations

As this is the first year of considering this data as a thematic report, it would be recommended that this document be updated every 2 years to consider how the updated figures compare and whether there are any significant changes to the data, themes or trends.

- It is recommended that a similar style report be considered for other causes of expected death (excluding Neonates) between 2016-2021, so that themes and trends can be identified, plus recommendations compared so that identified learning can be shared across the medical specialities.

It is also recommended that Surrey CDOP improve specific data collection of the following:

- Child's ethnicity
- Whether a cancer has relapsed
- Whether a child is known to Children's Services
- Whether a diagnosis is delayed for any reason
- Whether a child died in the family's preferred location
 - If not, why not?
- Whether an end-of-life care plan was in place
- How long prior to death was this care plan first discussed with the family
- Whether the Covid Pandemic has adversely affected diagnosis and waiting times for Cancer treatment

As the information, learning and outcomes increase with the creation of a Child Death Review Meeting for all deaths the richness of the data is expected to develop, and potentially greater learning may be identified from a thematic approach in future reports.