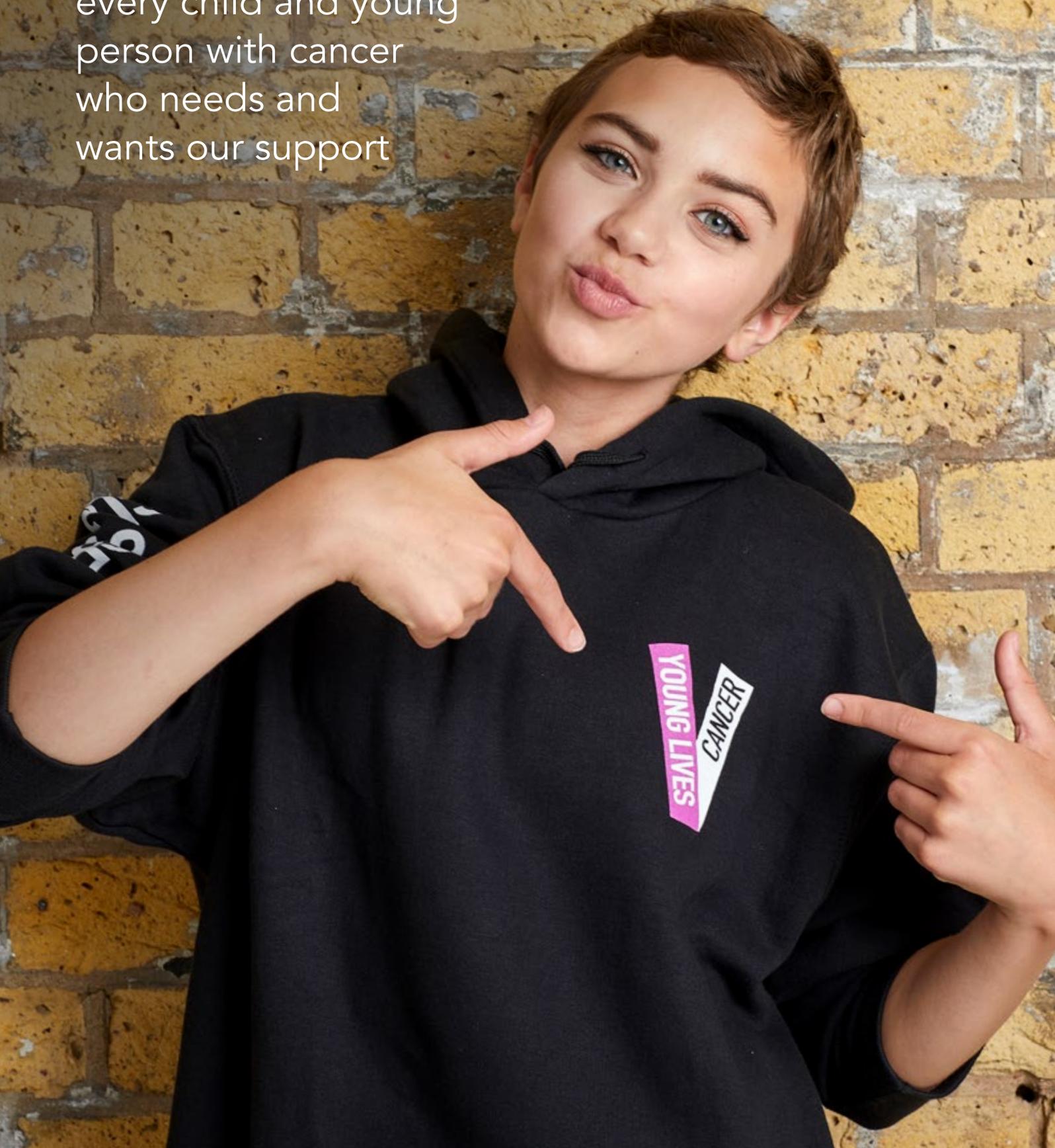


WHAT ABOUT ME?

YOUNG LIVES
vs CANCER
CLIC SARGENT

Striving to be there for every child and young person with cancer who needs and wants our support



INTRODUCTION

Every year 4,451 children and young people are diagnosed with cancer in the UK (CRUK, 2018). CLIC Sargent currently registers 3,068 of those – 1,588 children and 1,480 young people. To save you doing the maths, that's 69%, which means there are around a third of children and young people (CYP) every year who are not registered with CLIC Sargent. As a result there are children and young people with cancer who might not be receiving the age-specific support they need. We know that's not good enough. This problem is replicated in most organisations working with this group across the UK – for example, we know that 62% of 15 to 18-year-olds and only 39% of 19 to 24-year-olds with cancer were notified to a specialist treatment centre¹. But knowing this gap is not exclusive to CLIC Sargent doesn't make it any better.



CLIC Sargent's vision is that everyone under 25 with cancer, and their families, will get the support and help they need during their cancer treatment and beyond. We know that age-appropriate health and social care support is vital if the best possible outcomes are to be achieved both clinically and to protect the emotional, financial and long-term well-being of children, young people and their families.

This report aims to investigate the characteristics of CLIC Sargent's 'missing third', understand more about their diagnosis, where they are, their experiences and begin to set out our ambition for how many children and young people with cancer CLIC Sargent should be reaching. This is the start of a process through which we will be calling on clinicians, policy makers, fellow charities and our supporters to join together to ensure every child and young person with cancer receives age-specific care.

A key finding of this report shows the main gaps between CLIC Sargent registration data and national cancer incidence figures are with young people aged 15 to 24 and within eight key disease types.

¹ Catherine O'Hara et al, Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010

HOW HAVE WE PRODUCED THIS REPORT?

We identified four main areas of activity to develop the analysis we needed to find out about the 'missing third'.

AREA ONE

We analysed Cancer Research UK (CRUK) incidence data 2013 to 2015 against the registration data on CARE (our in-house database) 2013 to 2015 including children, young people and country breakdown.

AREA TWO

We analysed CRUK data on CYP cancer diagnoses, including 'adult' cancers with incidence in those under 24 years of age and identified gaps in our current registrations.

AREA THREE

We analysed CLIC Sargent data, sense checking against our young people's service evidence base and testing our long-held assumptions about where gaps are.

AREA FOUR

We collated information we currently have on children and young people whom we have recorded as 'Do not want a service' (DNWS).

Like with most data, there were some limitations. We have explained these in Appendix A.



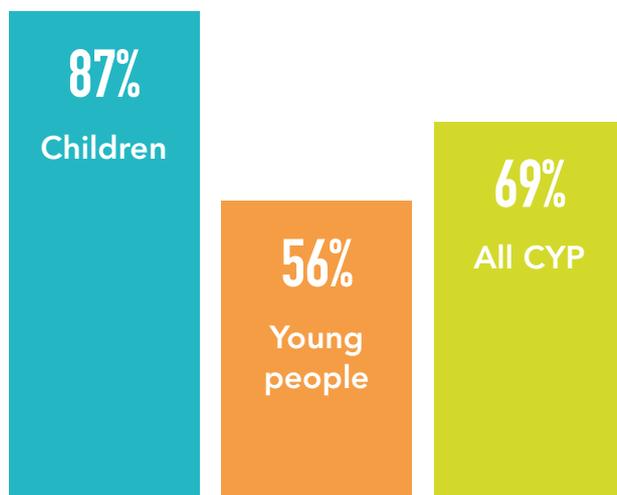
WHAT DID WE FIND OUT?

Who does CLIC Sargent currently register?

Analysis of CRUK incidence data against CLIC Sargent CARE registration data 2013 to 2015 found CLIC Sargent has registered an average of 3,068 children and young people diagnosed with cancer in the UK (1,588 children and 1,480 young people). This is shown in Table One below.

Table One: Age analysis of CRUK incidence data against CLIC Sargent CARE registration data for 2013 to 2015

	Children (0-14)	Young people (15-24)	All CYP (0-24)
CLIC Sargent registration data (diagnosed 2013 to 2015) ²	1,588	1,480	3,068
CRUK incidence	1,821	2,630	4,451
Percentage of CYP diagnosed registered by CLIC Sargent	87%	56%	69%
How many CYP diagnosed not registered by CLIC Sargent	233	1,150	1,383



FINDING ONE

The biggest gap in CLIC Sargent registrations is with young people

² We used data from CLIC Sargent 2013 to 2015 to be comparable with CRUK diagnosis figures. We are aware we have more up-to-date data from CARE (CLIC Sargent's in-house database) we could use but felt it was more important to be consistent with CRUK data.

What are the disease types of the missing third?

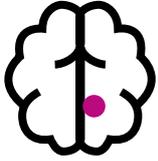
Analysis of CRUK incidence data against CLIC Sargent registration data between 2013 and 2015 found that whether a child or young person was registered by CLIC Sargent does depend on their cancer diagnosis. The data highlights eight disease types where the gap between the number of diagnoses and CLIC Sargent registrations was over 50 individual CYP.

Table Two: Analysis of CRUK incidence data against CLIC Sargent CARE registration data for 2013 to 2015 by cancer diagnosis

Cancer type	Number of CYP CLIC Sargent registers	Incidence (CRUK)	Percentage gap
Brain tumours	473	828	43%
Bowel cancer	15	191	92%
Melanoma skin cancer	69	208	67%
Lymphoma	539	671	20%
Testicular cancer	163	285	43%
Ovarian cancer	35	138	75%
Cervical cancer	33	95	65%
Bone cancer	109	166	35%

FINDING TWO

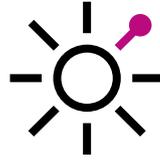
There is a difference in our registration numbers linked to eight specific disease types.



Brain tumours



Bowel cancer



Melanoma skin cancer



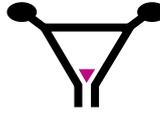
Lymphoma



Testicular cancer



Ovarian cancer



Cervical cancer



Bone cancer

FINDING THREE

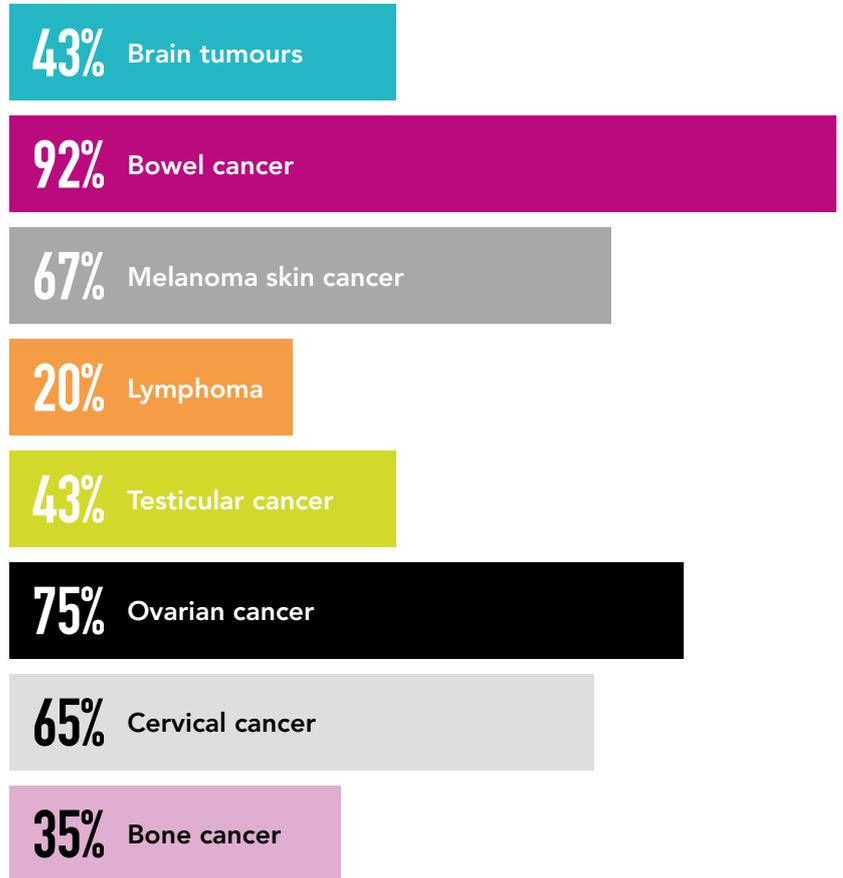
The highest numbers of gaps in our registration numbers of these eight specific disease types are in young people.

902

young people with one of the eight specific disease types are not registered with CLIC Sargent.

FINDING FOUR

Some of the disease types with the highest gaps in registration numbers appear to be those where the disease is less common in children and young people. This suggests those diagnosed may not be filtering through from adult services or their treatment pathway may be different.



FINDING FIVE

The largest gap in the brain tumour figures may be caused by a mix of neurosurgical pathways and the nature of the disease on a benign-malignant spectrum.



CYP with a brain tumour diagnosis registered by CLIC Sargent

CYP brain tumour Incidence

percentage gap in CYP with a brain tumour diagnosis registered by CLIC Sargent

What is the mortality of those eight specific disease types?

Nine children and young people die from cancer every week in the UK. That is around 520 deaths every year. Cancer is the most common fatal disease for children and young people aged 1 to 24 years old in the UK. Brain, other CNS and intracranial tumours are the most common cause of children and young people's cancer death.

We collated data on the mortality of the eight disease types to outline the impact they have on the lives of children and young people with cancer. **Of the eight disease types bone cancer and brain tumours have the highest mortality for children and young people.**

Table Three – Mortality data for the eight cancer types with highest gaps between CLIC Sargent registrations and CRUK incidence data

Cancer type	0-24 years incidence ³	Deaths ⁴	Deaths (%)
Brain tumours	828	153	18%
Bowel cancer	191	8	4%
Melanoma skin cancer	208	6	3%
Lymphoma	671	37	6%
Testicular cancer	285	4	1%
Ovarian cancer	138	6	4%
Cervical cancer	95	5	5%
Bone cancer	166	57	34%

³Incidence – Average cases per year 2013-15 (CRUK, 2018)

⁴Average deaths per year 2014-16 (CRUK, 2018).

CONCLUSION AND RECOMMENDATIONS

This piece of work has resulted in five key findings:

1. The biggest gap in CLIC Sargent registrations is with young people.
2. The biggest gaps are linked to eight specific disease types.
3. The highest numbers of gaps in our registration data of these eight specific disease types are in young people.
4. Some of the disease types with the highest gaps in registration numbers appear to be those where the disease is less common in children and young people. This suggests those diagnosed may not be filtering through from adult services, or their treatment pathway may be different.
5. The largest gap in brain tumours may be a mix of neuro-surgical pathways and the nature of the disease on a benign (low grade)–malignant (high grade) spectrum.

We know CLIC Sargent is currently registering 3,068 children and young people diagnosed with cancer in the UK (yearly average).

We have also identified eight disease types which have gaps of over 50 CYP between the numbers registered with CLIC Sargent and CRUK incidence data. These diagnoses are:



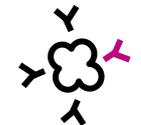
Brain tumours



Bowel cancer



Melanoma skin cancer



Lymphoma



Testicular cancer



Ovarian cancer



Cervical cancer



Bone cancer



CLIC Sargent will use this data as a basis for conducting various pieces of work to reach more children and young people who need our services. These will include:



Insight into the experiences of CYP with the eight specific disease types.



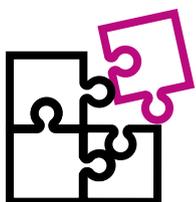
Work with partner organisations and professionals to further understand their pathways and support needs, and co-promoting services to create greater awareness.



Defining our core offer and communicating it to a wide range of audiences so CYP with cancer, and their families, are clear about how we can support them.



Insight into where CYP get their information and using that insight to develop appropriate content and channels to best reach them with information about CLIC Sargent's range of services.



Establishing a tailored data dashboard to continually monitor the reach of CLIC Sargent services.

WE NEED YOU

Age-appropriate specialist care and support should be a right of every child or young person diagnosed with cancer. This specialist support is vital to maintaining their well-being and achieving the best possible health outcomes through access to age-specific clinical trials, for example. It's simply not right or OK that there are more than 1,000 children, young people and their families affected by a cancer diagnosis out there who may not know CLIC Sargent exists, let alone the services we offer.

We want to hear from any healthcare professional, cancer charity, NHS Cancer Alliance leads or policy makers who can help us in our fight to get specialist care and support to everyone diagnosed with cancer under 25. It may save their lives, in more ways than one. Please contact us if you feel you can contribute in any way, however small, to tackling this challenge. We would love to hear from you. Contact us on whataboutme@clicsargent.org.uk or **0300 330 0803**





WHAT'S IN A NAME?

What about me? has been inspired by the children and young people who tell us what it's like to go through the isolating and scary world of cancer. Many find themselves sitting in adult cancer wards, wondering where the age-appropriate support is for them. Guys like Chris:

"I had to have my bladder, prostate and surround lymph nodes removed. I was facing a six hour operation, and even if I did make a full recovery it meant I couldn't have children. I was only 23 years old and being told I couldn't have kids. I was in the adult urology ward with people twice my age, who had the same operation as me. People old enough to be my parents.

"I became extremely isolated. I stayed in my room and didn't want to talk to anyone. I just felt really, really down about everything. I couldn't see the light at the end of the tunnel. I couldn't cope and I didn't feel like I had anywhere to turn. I didn't really feel like there was anyone I could turn to; I didn't know what support was out there and I didn't know where to look."

Our mission to support more children and young people is to make sure those diagnosed with cancer in the future never have to ask "What about me?"



References

Cancer Research UK

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers>
(Accessed July 2018)

Cancer Research UK

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/young-peoples-cancers>
(Accessed July 2018)

Cancer Research UK

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/>
(Accessed July 2018).

Appendix A: What data limitations did we work with?

We know that the datasets we are working with are imperfect. Therefore there were certain known limitations that we mitigated and also some areas where we made educated assumptions.

The limitations we were working with and how we mitigated them are outlined in the table below.

Issue	Impact	Comments or mitigation
Cases: CRUK data counts cases of cancer	Possible double-counting of individuals in CRUK data as they count cases rather than individuals.	Impact would be limited as double-counting would only occur where there are two primary cancer sites which we believe is rare in these statistics, eg bilateral breast cancer
Incomplete records	CRUK data is 98% complete – it can take 55 years to incorporate records from other sources eg death certificates	We have to work with the CRUK data that we have and understand its 98% completeness.
CRUK use different data years for some cancers	CRUK uses 2000 to 2008 data for soft tissue sarcomas and 2013 to 2015 data for all other CYP individual cancers.	We have to work with the data available.
Age groupings	CS and CRUK age groupings are different	We cut our data to match CRUK.

Issue	Impact	Comments or mitigation
Cancer types and CRUK data	Not all CYP cancer types are included in the CRUK CYP data.	We have checked CRUK data for other cancers in CYP and used it in this report.
CLIC Sargent data – registration year vs diagnosis year	Those diagnosed in 2013–15 would be more comparable to CRUK data, but there are around 300 people who are recorded as diagnosed in 2013–15 but registered earlier.	We believe this was before we tightened up our Service Standards: not to register for support until a confirmed diagnosis. We have accepted this as a limitation of the data and think our diagnosis figures are as accurate as possible.
Country of UK	We had a question over which CS data to analyse when looking at country of the UK – home postcode or place of first treatment.	We assessed data from a CYP’s first treatment centre rather than their home postcode as that is where the CRUK diagnosis is likely to be recorded.
The CRUK data for each individual cancer type is more than CRUK overall data for children and young people (CYP)	<p>Although data is recorded for CYP in all cancer types in CRUK data (2013–15), some cancer types are excluded from CRUK CYP-specific data on all cancers.</p> <p>We believe these are some benign brain tumours and bone marrow failure syndromes. Therefore there are fewer cases of cancer for CRUK CYP if each cancer type is looked at than total incidence figures for CYP.</p>	We accept this limitation and assume the impact is very small.

Project team

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Tracy Cosgrave, Associate Director, Digital Services

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A young boy with a prosthetic left leg is standing against a brick wall. He is wearing a black hoodie with 'CLIC SARGENT' written on the sleeve, light-colored shorts, and tan sneakers. He is holding a white sign with black and purple text. The sign reads 'YOUNG LIVES vs CANCER' in large black letters, with 'CLIC SARGENT' in purple letters below it. He is also making a peace sign with his right hand.

YOUNG LIVES
vs CANCER
CLIC SARGENT

Registered charity number (1107328)
and registered in Scotland (SC039857).
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