

AN EVIDENCE-BASED COMMENTARY ON THE
CROSS-SECTOR SYSTEM

UNDERSTANDING THE NEEDS AND WELLBEING OF CHILDREN AND YOUNG PEOPLE WITH CANCER AND THEIR FAMILIES

Applying systems thinking for
transformational change

A collaboration between:



Report by:



June 2024

"Our main hope for the future is that the North Star vision, which describes an ideal cancer pathway for children and young people, doesn't just stay an idea, but becomes a reality."

- Young people from the Small Circle research group

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FOREWORDS

From the charity partners:

Children's Cancer and Leukaemia Group
Ellen MacArthur Cancer Trust
Teenage Cancer Trust
Young Lives vs Cancer

Our organisations work with children and young people with cancer every day. We see the huge and lasting emotional, physical and financial devastation cancer often has.

Supporting them through this experience is a societal challenge that demands a collective approach, which puts children and young people with cancer and their wellbeing at the centre and shines a spotlight on the complex systems of care, information and support that operate around them.

To meet that challenge, we worked with Dartington Service Design Lab to carry out this research and be honest about what needs to change. We made sure the research included young people, parents, carers and siblings, whose lives are profoundly affected. We talked to professionals. And we included people who finished their cancer treatment up to 10 years ago.

The result is a unique set of findings, and a new list of questions.

This report shows much that is already recognised: the impact cancer has on wellbeing, not only during cancer treatment, but also many years later; and gaps in support. But the findings also tell us more about what people's needs are, when they arise and who they affect.

We can't tackle any one issue in isolation. Everyone working with children and young people with cancer needs to work together to create a future where children and young people have everything they need to navigate cancer in their own way, so that:

Every child and young person facing cancer receives care that's tailored to them. They feel informed and in control, and along with their families can make knowledgeable decisions about their care and future. They feel empowered every step of the way, facing no gaps in support or barriers to access. They have everything they need from the beginning of their cancer experience, during treatment and for as long as they need it afterwards.

We are calling this our 'North Star'.

All our organisations have different roles in reaching this vision - but we need to work together and be honest about where we are, what remains to do, and what is not yet being addressed. The response from charities and NHS bodies to this new evidence base shows there is the will to reach the system North Star together. As a sector, as a system, as a society, we have the power to make it happen.



From Tim Hobbs, Dartington CEO

This research is bold and courageous. It represents a big step for these four major children's and young people's cancer charities, who have put aside their organisational egos to explore the needs, gaps and challenges faced by children and young people affected by cancer and their families, collaboratively. This, in itself, is rare in the often fragmented and competitive charity, health and social care system, and should be applauded.

But more fundamentally, this research is underpinned by the bravery and vulnerability of young people affected by cancer and their families who have shaped this work by sharing their experiences, challenges and hopes for a more supportive, integrated and personalised system of care.

As you will read in the research, there are numerous challenges faced by those navigating cancer diagnosis, treatment, care or bereavement, as well as clear opportunities for ambitious and systemic reforms. Acting on this research and doing justice to the insights shared by young people and families, demands further bravery and ambition from policy makers, funders, commissioners and the health, social care and charity sector.

From parents involved in the Small Circle

We, and all parents, had different experiences depending on our child's diagnosis, age, support networks and even geography. Through supporting our children, we saw the impacts on them, their siblings and other parents and the clear gaps in the care provision for the whole family. We joined this research because we see this need and believe that this research is an opportunity to create actual impact and change. This collaboration between the research team, charities, stakeholders and those who have experienced cancer as children or young people on a personal level will benefit families with experiences like ours.

We found the research, meeting with the other parents and hearing how their experiences were different very enlightening. We felt listened to with no boundaries and had a chance to advocate for children and young people with cancer, particularly those who might not be able to advocate for themselves. It was an empowering, humbling and healing process.

We hope that these findings can be used effectively to increase the wellbeing for all families going through this journey, including for years post-treatment.

From young people involved in the Small Circle

We decided to get involved with this project as we wanted to help improve the support young people going through cancer treatment get. Even though the doctors and our family were amazing during our treatment, we and others our age felt overlooked.

Our experience with this project has been overwhelmingly positive. The level of input we had as participants was valuable, even though it was hard to discuss parts of our experiences. We received nothing but encouragement and praise from the research team, allowing us to open up to them about what was a really hard time.

Our main hope for the future is that the North Star vision, which describes an ideal cancer pathway for children and young adults, doesn't just stay an idea, but becomes a reality. We also hope to see more support for people leaving treatment, including more information on things you may encounter as a result of treatment. We hope sharing our experience makes a difference, and we're grateful to [the partnership] for giving us the opportunity to express our views on the support that we experienced throughout our journeys.

EXECUTIVE SUMMARY

This report presents the findings of extensive research conducted collaboratively by Dartington Service Design Lab and children's and young people's cancer charities, shedding light on the experiences of children, young people and families affected by cancer. Engaging over 1,500 individuals, including young people, parents and carers, siblings and professionals, the research reveals critical insights into their needs, challenges and experiences of the support they received throughout their cancer journey.



Implications for systems of support:

The findings underscore systemic gaps in addressing the mental health and social impacts of cancer care which have profound consequences for long-term wellbeing and quality of life. This necessitates a holistic approach that integrates emotional support seamlessly into clinical pathways. Furthermore, wellbeing support is required long-term. Additionally, attention must be directed towards addressing the distinct needs of minoritised groups, siblings and bereaved families, ensuring inclusivity and responsiveness in support services.

Before treatment

Qualitative research participants described their experience leading up to diagnosis as being marked by stress and anxiety. Receiving a cancer diagnosis can be traumatic and rarely is there sufficient time or headspace to process the information. This may be compounded by challenges in accessing adequate support from healthcare professionals. These challenges are particularly heightened for families already struggling with pre-existing financial burdens and limited social support.

48%
of young people, parents and carers wanted more support to understand their or their child's diagnosis.

During treatment

Beginning treatment and getting accessible and timely information about this is challenging. Financial and practical pressures further compound the emotional toll on families, while feelings of anxiety and isolation permeate the treatment experience. Unsurprisingly, young people undergoing cancer treatment, and their parents, carers and siblings, report poorer wellbeing and quality of life, and higher cancer-related needs than those after treatment.

After treatment

After cancer treatment, young people and families report better wellbeing and quality of life. However, even years following treatment, wellbeing is still below that of the general population and emotional challenges persist, with anxiety spiking during follow-up tests. The sharp decline in signposting to relevant support after treatment leaves individuals feeling isolated and struggling to access the necessary support. In the years following treatment, we see an increase in needs from young people who find it hard to reconnect with support for their wellbeing.

The quality of life for young people and their families was on average 8% worse during treatment than those after treatment.

Young people who were treated for cancer have 36% higher anxiety than the population at large, and this remains true more than six years after treatment.

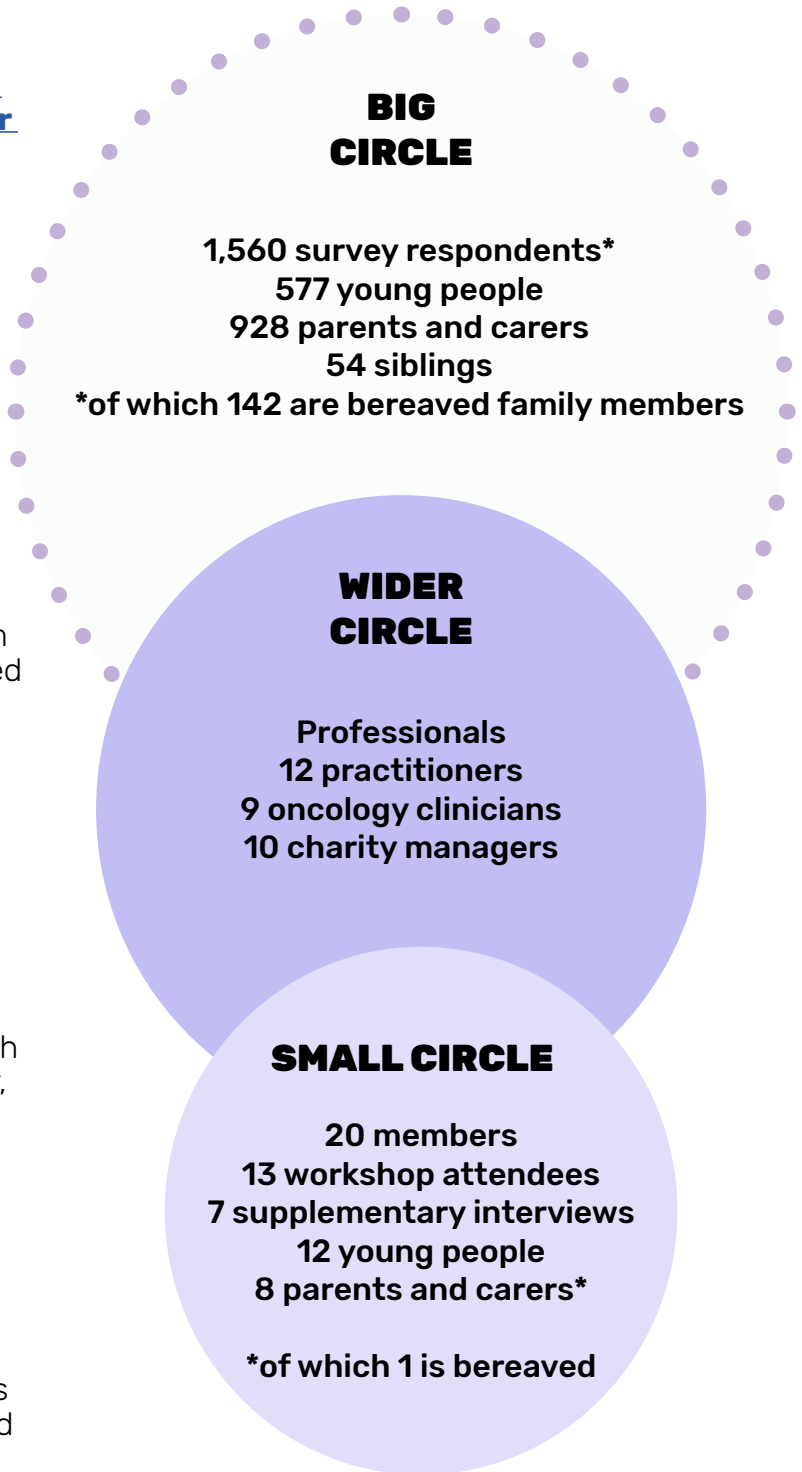
INTRODUCTION

This report presents the findings of research undertaken by [Dartington Service Design Lab](#) in collaboration with [Children's Cancer and Leukaemia Group](#), [Ellen MacArthur Cancer Trust](#), [Teenage Cancer Trust](#) and [Young Lives vs Cancer](#). Aspects of the research were supported by Professor Nick Hulbert-Williams at Edge Hill University.

The research engaged young people diagnosed with cancer, as well as parents and carers, siblings, social workers, oncology clinicians and charity managers. In depth contributions came from a 'Small Circle' of parents and young people, who shared their experiences and helped shape the research and survey design. We also engaged a 'Wider Circle' of professionals from the health and charity sector who participated in interviews and focus groups. We then conducted a large-scale survey reaching a 'Big Circle' of more than 1,500 people to capture a wider cross-section of cancer care experiences. This approach allowed us to gather a breadth and depth of insight, and an opportunity for young people and their families to shape the research.

The survey explored wellbeing and quality of life and factors which may impact these, such as the social and emotional impact of cancer, practical needs and the support received. More detail on the methods and measures used can be found in [the appendix](#).

The findings provide unique insights into the needs and wellbeing of children, young people and their families throughout their cancer journey, resulting in practical recommendations to strengthen the systems of support around children, young people and their families.





FINDINGS

BEFORE TREATMENT

The qualitative findings from the Small Circle and the Wider Circle reveal key issues impacting the wellbeing and quality of life of children, young people and their families, such as the anxiety and trauma of the diagnosis experience, and how financial and social contexts may compound the experience.

Stress and anxiety

Respondents shared concerns about being dismissed or misunderstood when they first noticed symptoms. Many young people, or their parents and carers, had to repeatedly request investigations and saw a decline in their health before their concerns were sufficiently investigated. This impacts trust in clinicians during treatment – and can be a barrier for clinicians to overcome and rebuild trust. While heightened before treatment, high anxiety persists for young people and their families throughout their journey: young people who responded to the survey reported 48% higher anxiety than those of similar ages in the population at large (Office for National Statistics, 2023a).

9 **OUT OF 12**
of the small circle
members reported they
received the
lowest level
of support in their journey
before diagnosis.

**“I had to seek external
therapy that wasn't
provided by the
hospital to cope with
medical anxiety.”**

– Young person

Trauma

We heard about how a diagnosis is communicated can be overwhelming and traumatic. Young people and their parents and carers are often overwhelmed by the urgent move to treatment as they try to process information. Many do not have time to digest, ask questions or discuss concerns. This means support offered at this time can be difficult to engage with. Clinicians can find it hard to communicate well with families and to understand their needs because they have limited time during appointments and fast-paced treatment regimes. Where clinicians are able to support families well, they work as part of multidisciplinary teams.

“I’d just like clear knowledge on what my diagnosis is, what it means for me in daily life right now and long-term, if I’ll be OK afterwards. Just clarity and simplified terms.”

– Young person

Pre-existing financial strain

We heard in the Small and Wider Circles that more families have social care needs, particularly stemming from the financial burden, that are not being met by statutory services. These issues, which affect all families, are compounded by the financial burden of cancer, which is covered in a later section on experiences during treatment.

“I would improve financial support, missing work and high fuel costs to get to appointments.”

– Sibling

DURING TREATMENT

Unsurprisingly, during treatment young people, parents and carers have lower wellbeing and higher levels of cancer-related needs than those after treatment. The research revealed struggles related to starting treatment, accessing support and information at the right time, and a lack of resources to navigate the financial, practical and emotional impact of cancer.

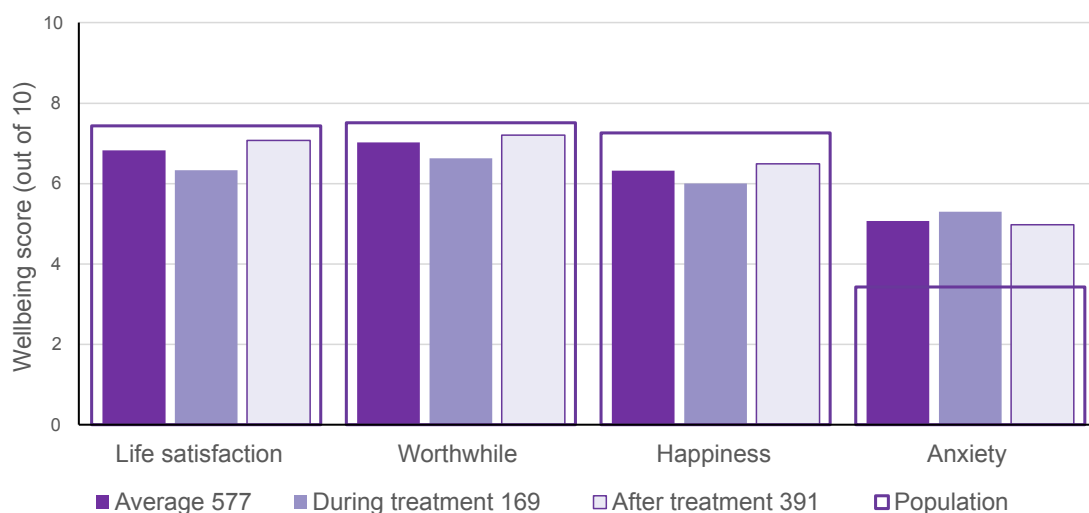
Beginning treatment

Through the Small Circle work, we heard that following an often prolonged and stressful diagnosis experience, the transition to treatment is a disorientating time for young people and their families. Once they receive the difficult news that they have cancer, things then move very quickly. Those having to make decisions about treatment describe having a lack of sufficient information and understanding to inform the choices they make.

“We were bombarded at the beginning when it was all very overwhelming so we didn't necessarily retain information or need everything at that time.”

– Young person

Figure 1. Young people's wellbeing by treatment phase



Information needs

There was a high need for information from both young people and parents and carers. This echos a common finding in the Small Circle, that information needed to be shared in a way that allowed them to process and digest it.

This was particularly so for longer-term impacts of treatment. For example, only 38% of respondents reported that they received support to understand the impact of treatment on sex and fertility and 36% of those would have liked more support.

“Perhaps someone mentioned all the support, but at the time of my child's diagnosis, I couldn't focus or remember anything.”

- Parent or carer

| | | Young people's needs by treatment phase | | | | | |
|------------------|-------|---|------------|------------|----------|---------|---------|
| | Count | Information | Assistance | Recreation | Feelings | Friends | Support |
| During treatment | 143 | 25 | 22 | 18 | 24 | 23 | 24 |
| After treatment | 338 | 20 | 18 | 15 | 21 | 18 | 20 |

Figure 2. Young people's needs by treatment phase. Colours are relative to the needs for each treatment phase. Dark purple shows higher needs and lighter purple shows lower needs.

Financial and practical pressures

In the Small Circle, parents and carers described the stress brought on by increased financial pressures during treatment: costs of travel, staying near specialist hospitals or because one parent or carer stops working to provide care for their child. On top of these financial pressures, in the survey, we found that respondents who had completed treatment had higher household incomes and were more likely to be employed than respondents who were still undergoing treatment. More information about cancer-related costs can be found in ['Cancer Costs', a report from Young Lives vs Cancer.](#)

43% of survey respondents said they received the support they needed related to financial help or benefits, but 38% said they needed more support and a further 12% needed support but said they didn't receive any. Social workers reported that while parents and carers might get support from their employers following the first diagnosis, employers can be less accommodating if their child has a recurrence, adding to the financial burden and stress.

Isolation

Young people in the Small Circle reported feeling isolated, 'labelled' by their diagnosis and that their peers did not understand their experiences. They shared the importance of meeting others with similar experiences, such as on wards or through charities and peer-support groups.

However, young people also often experienced bereavement of friends they made during or after treatment. While these relationships were valuable, several young people in the Small Circle spoke of the intense distress they felt when they saw friends die. **Only 35% of young people who reported needing it received enough support around bereavement, and 36% reported not receiving any support.** As well as being a traumatic loss, it also made them less optimistic about their own prognosis.

Parents and carers reported a disconnect and limited support from friends and family during treatment. In the Small Circle and the qualitative responses, parents and carers told us they would have liked to be connected with those going through similar experiences to them.

Inequality of care experience

Young people reported having different experiences in different hospitals. Generally, they described receiving good quality of care in specialist hospitals (particularly teenagers, who may feel out of place in children's or adult wards). However, experiences in non-specialist hospitals were mixed.

"I wasn't prepared to feel so drastically isolated and different."

- Young person

**Only half (50%)
of young people and
45%
of parents and carers
said they received support
to connect with others.**

“I needed to talk to other parents. They are the only ones to fully understand the anxiety, loneliness and scared feelings.”

– Parent or carer

AFTER TREATMENT

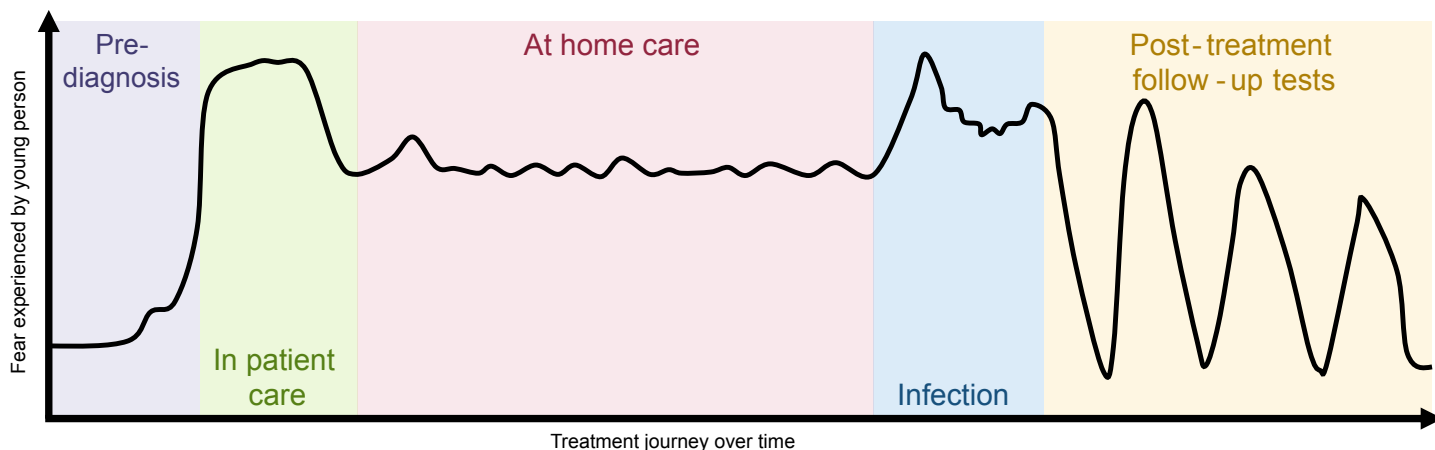
Young people, parents and carers that had made it through treatment showed improved wellbeing and quality of life scores, and lower cancer-related needs. But they still reported lower wellbeing than the general population, and many cancer-related needs persisted beyond treatment.

Post-treatment anxiety

The Small Circle reported a sharp decline in the support they received once treatment had finished. For many, this was the time when they started to feel the impact of the trauma they experienced. Several parents and carers and young people reported that they had been offered counselling during treatment, but that they were too overwhelmed at that point to access it. Once they felt ready, they were not always sure where to turn for help. Immediately following treatment, most young people described how their anxiety would peak as they approached follow-up tests and awaited results. However, as they went back for further tests, and follow-up appointments became less frequent, their anxiety decreased.

In the survey, we saw better wellbeing and quality of life for those post-treatment. However, respondents who were further from treatment reported only slightly better with regards to these measures than those who just finished.

Figure 3. Graph drawn by young person showing their fear over time.



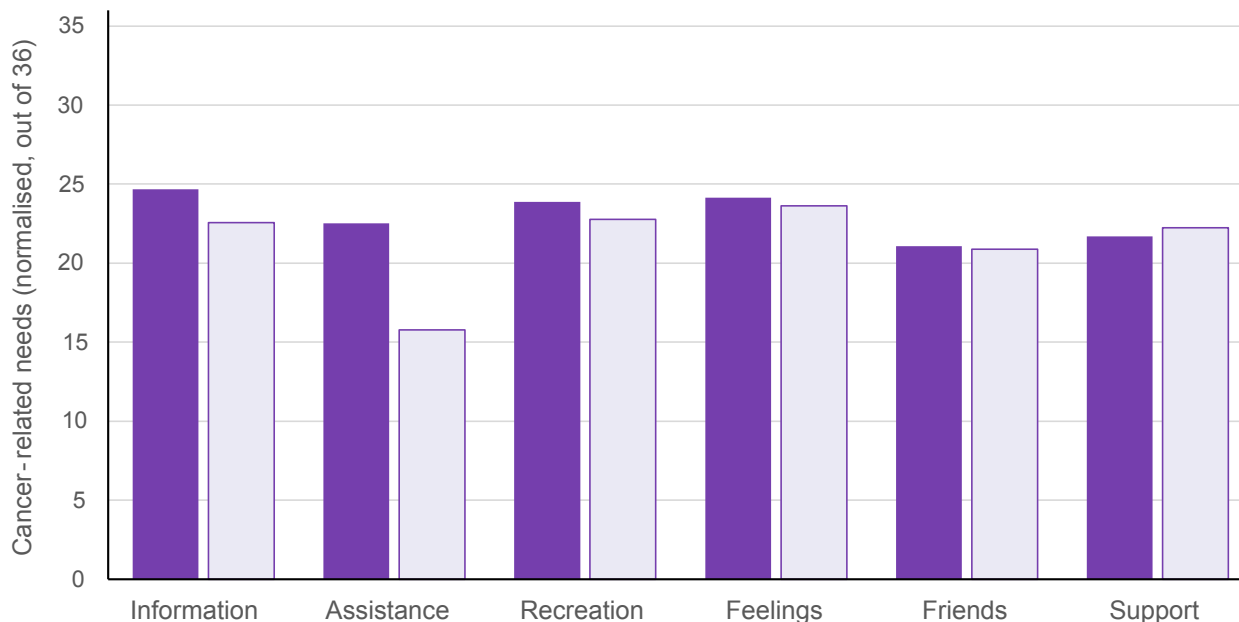
Five to six years after their treatment ended, young people's cancer-related needs tended to increase. Reconnecting with support at this time is challenging because they may not remember which services they previously engaged with and can't find information or support to re-engage. The structure of the health system and aging out of children's or young adult care means they are unable to reconnect with clinicians who held a previous relationship with the young person and family.

Life transitions after treatment, for example moving into the workplace or going to university, may prompt young people to reflect on their experiences. This, as well as late effects of treatment, can bring back trauma they experienced during their journey or trigger confusion in understanding their identity as someone who has had cancer. Moving into a new environment can prompt difficult decisions about disclosure.

"I found the lack of aftercare disappointing. To go from years of being closely monitored and cared for, to just being entirely on my own was terrifying."

- Young person

Figure 4. Average needs of young people and parents and carers by time since treatment



NEEDS FOR DIFFERENT GROUPS

Bereavement

Bereaved family members report lower wellbeing and have distinct cancer-related needs compared to those who are not bereaved. They prioritise their needs around feelings, recreation and support.

Greater availability of counselling was frequently requested for bereaved parents, carers and siblings. **34% of bereaved parents and carers reported not receiving support around bereavement**, 60% received support but of those, 34% of respondents said they wanted more. Bereaved parents were less likely to receive enough support to connect with others: 28% of bereaved parents compared to 42% of non-bereaved parents.

The survey had a low response rate from young people undergoing palliative or end of life care, which limited what we can say about their experiences. This group may have unique needs and it is an important area for further research.

“There was a lack of help and support after I had lost my son. I was totally alone and felt that life was not worth living.”

– Parent or carer

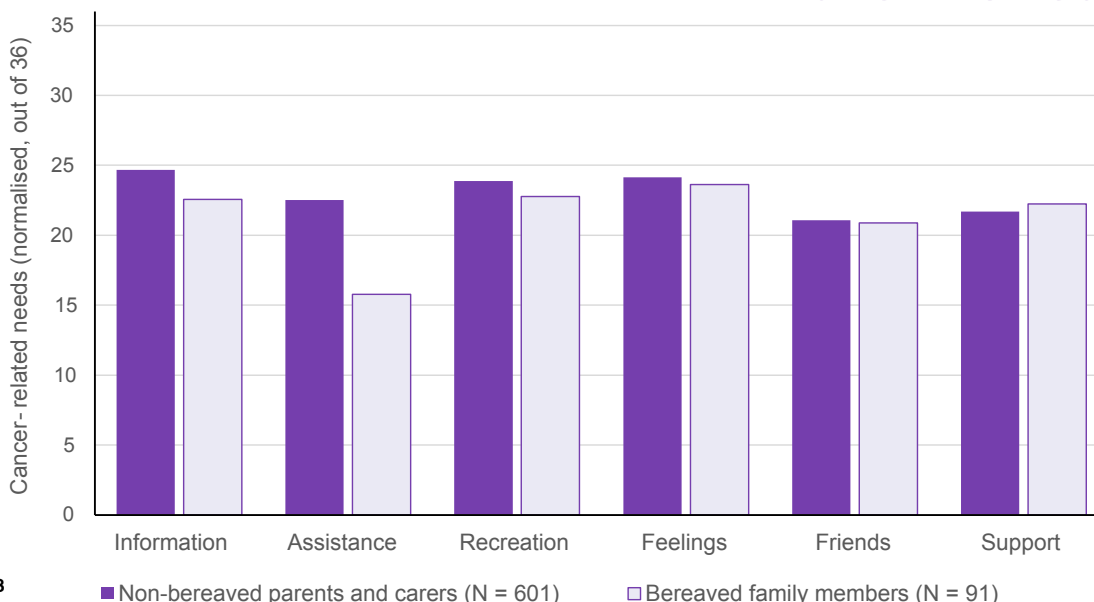


Figure 5. Bereaved family members' needs compared with non-bereaved family members

Siblings

A consistent finding throughout this research is that the needs of siblings are often overlooked. While the numbers of siblings participating in the survey is relatively low (n=54), the findings are consistent. Siblings reported greater needs and lower wellbeing than the other response groups. They described how they rarely had any formal support or sources of information specific to them. This was particularly challenging as they often subsequently took on critical caring responsibilities at a young age. They may also experience their own challenges around bereavement. Siblings reported particularly high anxiety when compared to a similar-aged population.

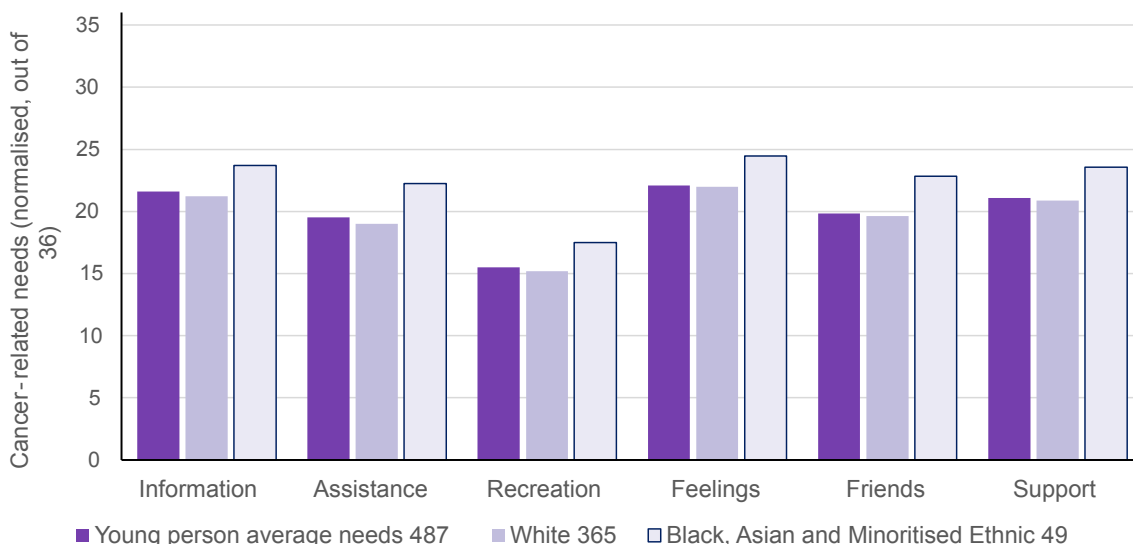
“I often felt like the siblings got forgotten about. I was living with my brother and taking on a lot of the caring role of a parent as well, but I felt like no one really checked if I was OK, it was always him and my parents they were checking on.”

- Sibling

The experience of minoritised young people and families

All response groups (young people, parent/carers and siblings) at all points in their journey had worse wellbeing than the general UK population. Though needs varied for different groups at different points, they were consistently higher for LGBT+ young people, and Black, Asian and Minoritised Ethnic young people.

Figure 6. Young people's needs by ethnicity



SUMMARY OF FINDINGS

The research has provided invaluable insights into the experiences of children and young people affected by cancer and their families, highlighting key features regarding their needs, challenges and support.

The impact of cancer for children and young people encompasses more than the impact on their physical health – social, wellbeing and mental health impacts are pronounced throughout diagnosis and treatment and typically persist for many years.

When a diagnosis is made, young people often report feelings of stress and anxiety – a diagnosis can be overwhelming and traumatic. During treatment, emotional, practical and financial pressures weigh heavily.

The findings underscore the complex impact of cancer on the wellbeing of those affected. Though support is high during treatment, it is hard to focus on holistic mental health and wellbeing needs at this time. Existing systems of support struggle to respond to the distinct challenges faced by marginalised groups, bereaved families and siblings.

The research highlights the acute financial strain faced by families during and after cancer treatment. For those already struggling, this can be devastating and significantly compound stress, anxiety and the ability to access support.

Following treatment, support decreases suddenly and significantly. While needs are lower after treatment, as time passes young people and families may start to notice the accumulated impact on their wellbeing. Young people and families often feel isolated. If they do reach out for support, they often have difficulty accessing it because they are no longer eligible, don't have the relevant contact information or are out of referral and signposting pathways.

This research highlights how the system is insufficiently resourced to provide the necessary psychological, social and financial support required to navigate what are the most challenging times experienced by children, young people and their families.

IMPLICATIONS FOR SYSTEMS OF SUPPORT

This research suggests a variety of ways in which the systems of support around children, young people and families may be strengthened during and after what may be some of the most challenging periods in their lives:

- Integrate high-quality, clinically sound information about different forms of cancer and treatment throughout the cancer care pathway, and ensure it is tailored and accessible to diverse audiences, at the times they need it most.
- Create a high-quality and consistent model of social and psychological support – during but crucially after treatment. Timeliness and flexibility in access to such provision is crucial – support may be required many months or years after treatment when young people and families are able to engage with trauma or new realities.
- As well as formal models of psychological support, there is a critical role for informal and peer models of support – and the strengthening of infrastructures and resources to enable such support networks to thrive, in a consistent way across the UK and at scale.
- Whole-family support is required, not just for children and young people directly experiencing cancer, but also targeted support for their parents, carers and siblings and their specific needs – during and after treatment, and for those experiencing bereavement.
- Existing systems of support are not well equipped to recognise and respond to the distinct needs and challenges faced by marginalised or minoritised groups (such as different ethnicities, those identifying as LGBT+, or those with other physical or mental health conditions). By amplifying the voices of these marginalised communities and co-designing and tailoring supports to their specific needs, we can strive towards a more equitable and compassionate cancer care landscape.
- The financial impacts of cancer on families cannot be understated. For those already stretched, it can push them towards hardship. Policy changes are required to provide temporary financial cover for families during these most precarious times.

All of these reforms cannot be consistently achieved at scale by any one organisation within the sector. It will require a systemic and coordinated approach, with different partners within the sector identifying the role they are best placed to play in contributing to change.

NEXT STEPS

It is hoped that this research will further enable organisations providing support and resources to children and young people impacted by cancer and their families to strengthen existing provision and start to fill identified gaps and needs.

The charity partners involved in commissioning and shaping this research are committed to collaboratively working with partners across the wider sector to strengthen systems of support across the country, so that all children and young people impacted by cancer and their families get the best support they need, when they need it.



Children's Cancer and Leukaemia Group

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers. Our network of dedicated professional members works together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative, world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.



The Ellen MacArthur Cancer Trust

The Ellen MacArthur Cancer Trust is a national charity that takes young people aged 8-24 on sailing and outdoor adventures to inspire them to believe in a brighter future living through and beyond cancer. For many young people, simply picking up where they left off before their diagnosis just isn't possible. So, when treatment ends our work begins. Through our sailing and outdoor adventures, young people feel more accepted, independent and optimistic as they start to re-establish their purpose and place in the world after treatment.



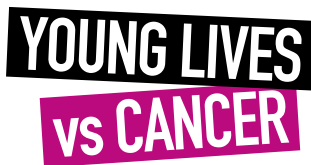
**DARTINGTON
SERVICE
DESIGN LAB**

Teenage Cancer Trust

Since 1990, Teenage Cancer Trust's nurses, youth support coordinators and specialist hospital units have been at the forefront of providing life-changing care for young people with cancer.

Teenage Cancer Trust has pioneered the development of treatment and support specifically for teenagers and young people with cancer, which didn't exist in the UK before the charity formed in 1990.

Teenage Cancer Trust has 28 purpose-built units within NHS hospitals which are places where young people aged 13- 24 can feel at home, meet others their age, and welcome family and friends, while being looked after by a dedicated team of specialists.



Young Lives vs Cancer

When a child or young person is diagnosed with cancer, their whole world (and their family's) can feel like it's falling apart. Their anxieties are deep. Their education, mental health and social lives suffer. Their futures feel very uncertain.

Young Lives vs Cancer's specialist social workers provide tailored psychosocial support to children and young people with cancer (0-25), and their families. We stop at nothing to make sure they can get the right care and support at the right time.

Dartington Service Design Lab

Dartington Service Design Lab is a research and design charity focused on using and generating evidence and design in innovative ways to help those working with children and young people have a greater impact. As an organisation, we have more than 60 years of experience working across the public and voluntary sectors to help give children the best start in life, grow up safe and cared for, and have good mental health and wellbeing. We work at the intersection of evidence-informed practice and user-centred design, taking a 'systems thinking' approach to our work.

APPENDIX

Research methods and demographic information

Qualitative research

Dartington Service Design Lab held a series of four workshops and one-off interviews with young people, parents and carers that formed the Small Circle. One workshop was held in-person and all others took place online. These workshops focused on their experiences of their cancer journeys and reflections on the insights of the research.

Supplementary interviews were also conducted with parents and carers and young people from marginalised backgrounds to ensure their experiences were represented in the research.

The Wider Circle consisted of a workshop with 12 social workers, two focus groups with nine oncology clinicians, interviews with 10 senior charity managers and two workshops with staff from charity partners.

Data from the Small and Wider Circles were gathered using workshop activity sheets and through facilitator notes. These were then themed and analysed using systems thinking concepts.

| Engagement type | Number of young people | Number of parents and carers |
|-----------------|------------------------|------------------------------|
| Workshops | 7 | 6 |
| Interviews | 5 | 2 |

Survey

The survey was constructed by Dartington Service Design Lab with input from Edge Hill University. A workshop with the Small Circle was held to get input and feedback on the survey design.

The final survey asked respondents about themselves, their diagnosis, treatment phase, time since treatment, treatment centre, where they live and demographics. It also asked about

their wellbeing, using an Office of National Statistics (ONS) instrument and compared the data to ONS findings of the population at large. It also measured quality of life using the World Health Organisation Quality Of Life instrument and a [series of tools from Canteen](#), measuring cancer-related needs. Finally it asked respondents about the support they received related to specific areas (e.g. to understand fertility) and whether they received support from specific organisations.

Descriptive statistics were conducted on the data and used to generate the graphs and tables included in this report. These calculations looked at average responses in different groupings

Respondent demographic information

We included 1,560 responses in the analysis upon which these findings are based. At the end of the survey, we included some questions about the demographics of the respondents. For each of the questions, there was an option for respondents to not share, and some of the respondents did not reach this part of the survey, but still provided us with enough data to use in other areas of the analysis.

A large majority (88%) of the respondents who gave their ethnicity identified as white (excluding Romani and Irish travelers), which was true for all response groups. Only two (5%) of the siblings group who provided information on their ethnicity were Black, Asian or Minoritised Ethnic.

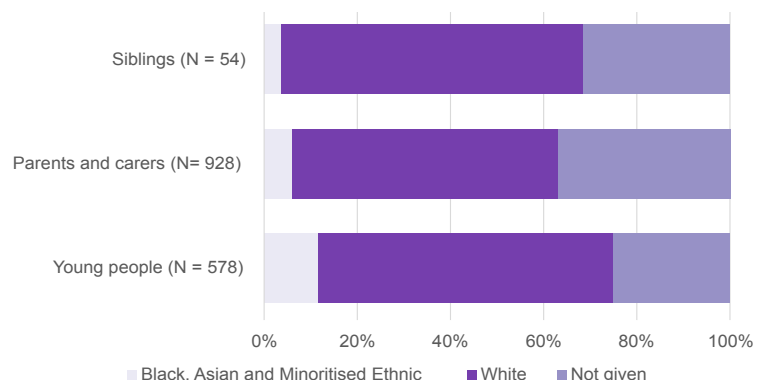
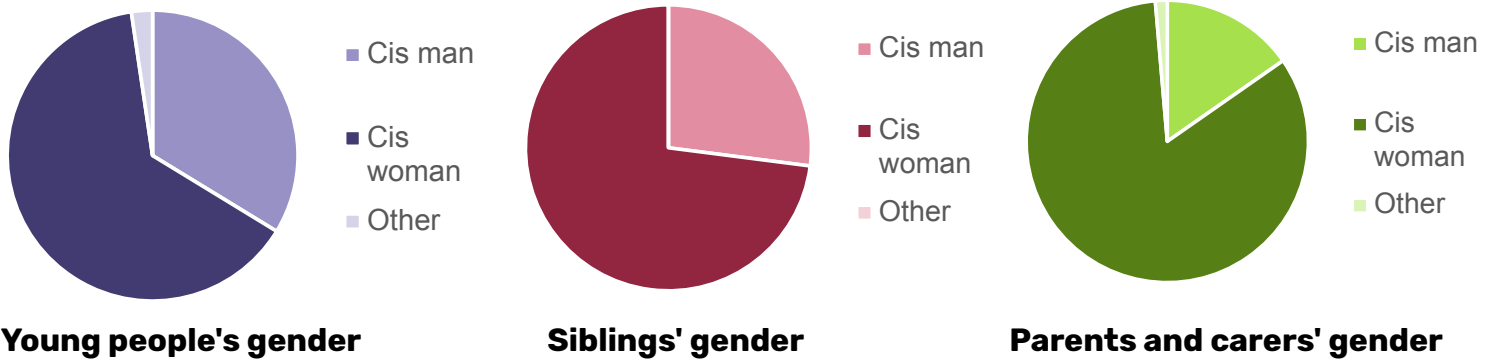


Figure 7. Ethnicity of response groups

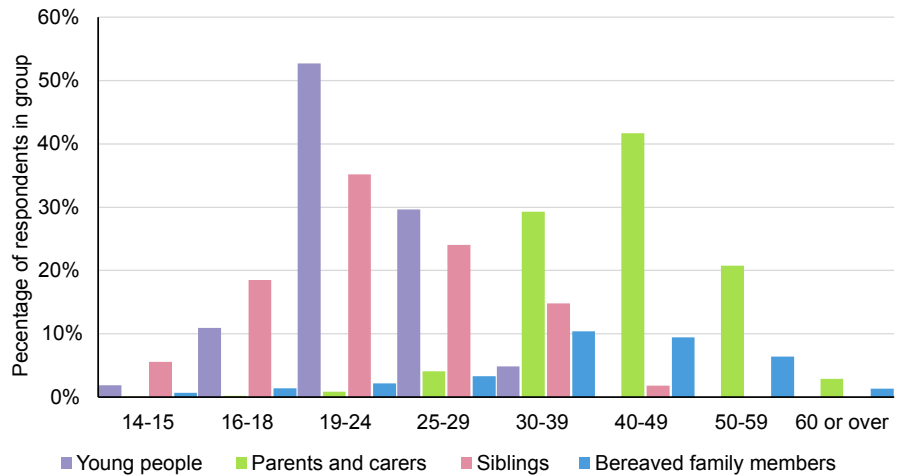
There was a disproportionate number of women answering the survey, which was particularly pronounced for parents and carers (83%), but still persisted for young people (64%).

Figure 8. Genders of response groups



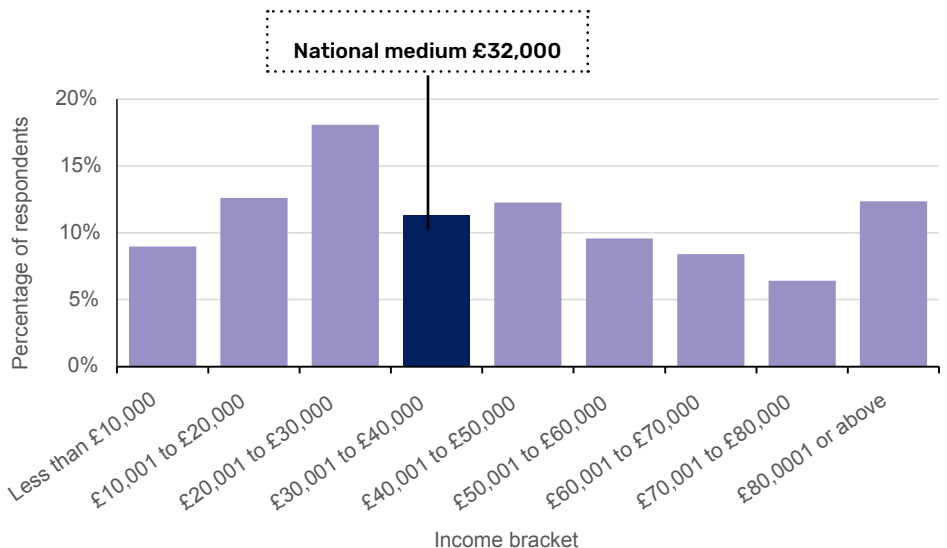
More than half (53%) of young people who responded to the survey were aged 19-24. Most commonly (42%) parents and carers were aged 40-49. Siblings were more distributed in their age than other response groups.

Figure 9. Ages of response groups



On average, respondents had slightly higher incomes than the population at large – more respondents had higher household incomes than the national median (ONS, 2023c).

Figure 10. Incomes of response groups



APPENDIX

Limitations of the research

The Small Circle provided rich and in-depth data engaging both parents and carers and young people. However, it only involved few people and is therefore difficult to generalise the findings. This limitation was mitigated by drawing on the quantitative responses from the wider-scale survey. Partners working in this space are sensitive to the fact that people from marginalised backgrounds are currently under-represented by the sector. The supplementary interviews in the Small Circle specifically sought to redress this by reaching out to disabled or Black, Asian and Minoritised Ethnic parents, carers and young people.

The survey had a lower response rate from siblings, which limits confidence – although findings are broadly consistent in their patterns across question-sets. Likewise, there were only eight young people who were receiving palliative care. Because the Small Circle, Wider Circle and survey respondents were recruited through opportunity sampling, respondents could be biased in several ways. Firstly, the reach is limited to those who were more engaged with services provided by partner organisations who promoted the survey. Secondly, those motivated to participate in the research may have different experiences from the wider population of those with experience of cancer.

The measures used in the survey only consider the wellbeing and needs from respondents at the time of completing the survey, and therefore does not compare individual people's experiences at different times. This may bias the interpretation for those who had different experiences at different points (for example those whose treatment was impacted by COVID-19).

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