OUR OUTCOMES & IMPACT

Making sure what we do benefits all children and young people with cancer, and their families.

Blog update – July 2025

We want to help children, young people and their families get through the devastating effects of cancer. We know that the work we do has a huge impact on children, young people and their families because **they tell us how much we've helped every day.**

But it is also important that we invest in rigorous measurement to develop evolving evidence of what works to improve outcomes and impact for children and young people with cancer and their families. We want to continually understand what works for who and under what circumstances – and to share that as widely as possible– being honest and transparent about what we find, including what is working and what is not working or needs improvement. Continually learning in this way helps us to shape both our own services, as well as the wider system of support that surrounds children, young people and their families. Taking this 'whole system' approach means we can deliver the best support possible for all children and young people with cancer, and their families.

Our next 'Impact Report' will be published in 2026. We are doing a huge amount of work, with children and young people, families, partner charities, and measurement specialists to build on and improve our rigorous impact measurement. This blog shares what we are doing, what we know already, and invites collaboration as we move forward:

- Research into the 'State of the System' – establishing the baseline and testing new measures of outcomes and impact
- Our North Star vision – as the foundation of our outcomes and impact
- Where we are now – what we are currently measuring and why
- What's next – creating a culture of learning.

Research into the ‘State of the System’

Since we published our last Impact Report, our focus has been on conducting a large-scale, collaborative piece of foundational research with Dartington Service Design Lab and three of our charity partners, which explored the experiences of children, young people and families during cancer and the impact this has on their lives. The State of the System report draws on data from around 1,500 young cancer patients, siblings, parents and carers and gave us a detailed understanding of the level of need for support, both during, and beyond, cancer, and the impact that cancer as a child or young person has on wellbeing over time.

Investment in this research is enabling us to hone the outcome measures we use, and establish a baseline that we will now be using to measure wellbeing in the future. We made a conscious choice during this time to reduce some other parts of our regular survey programme, to ensure we were not surveying the same group of people on similar things at the same time and cause confusion or distress to families. This has been a deliberate approach to overhaul and strengthen the measures, and ensure that they address the priorities of children, young people, and families.

Our full survey programme is now live again, and we are planning our next Impact Report for 2026.

Our North Star vision

The North Star – published in 2024 - is a vision for a better future for children and young people with cancer and their families. It is collective – meaning it is not just our vision – but should be a vision for the whole system of support. It was created in partnership with CCLG: The Children & Young People’s Cancer Association, Ellen MacArthur Cancer Trust and Teenage Cancer Trust. It guides how we understand impact, and impact measurement, to create a better future for children and young people with cancer, and their families.

Within Young Lives vs Cancer we have a ‘Theory of Change’ – a simple illustration of how our work contributes to the North Star vision. But we know changing the experiences of children, young people and families is complex. The problems that children and young people with cancer face are more complex than can be addressed through one organisation on its own. That’s why we are working as part of the North Star Collective, aCollective Impact Initiative which is bringing together organisations in a structured way to improve outcomes for children, young people and their families and to learn and improve together.

Where we are now

We are guided by the five types of data framework, as recommended by Impact Measurement specialists New Philanthropy Capital (NPC) as part of their Inspiring Impact programme.

User, **engagement**, **feedback**, **outcomes** and **impact** data is fundamental for monitoring and evaluating our services and continually learning what works to improve outcomes for children and young people with cancer and their families, in which context. The core set of metrics which we routinely measure is set out below – along with some of the latest results.

What we measure and how we use it:

Data type	What we collect	How we use it	Here are a few examples of current data
User data *Who are we reaching? What are their needs?*	● Information on people's demographics and the kind of cancer treatment they are experiencing	User data helps us every day to deliver, plan and resource our service in the most effective way. It also helps us, in the longer term, to take a step back and understand the people we are supporting and how that is changing over time.	Last year (between April 2023 and March 2024), we supported 6,849 children and young people with cancer. 3,004 were new registrations during the year. Of those we supported last year, 56% were aged 0-15, 38% were 16-24 and 5% were 25 or over (due to continuing support provided to those who would have been aged 25 when they were newly registered.) We are working on a project now to get better access to and do more with the wide range of user data we collect.
Engagement data *How are they using our service? Are there groups we are failing to engage?*	• Number of children, young people and families we reach with different services we offer and the interactions we have with them, and the value of the financial support they access	Engagement data give us vital feedback on whether our services are being used, and to what degree, as well as understand the **volume, or scale**, of outcomes and impact. Like user data, engagement data helps to deliver, plan, and resource our service. They also help us to hold	Last year (between April 2023 and March 2024): - We provided 5,057 grants spending £840,879. Our financial hardship grants support young cancer patients and their families who are struggling the most –

	• Where they are, and where they are in their cancer experience (for example, were they recently diagnosed) • Number of children, young people and families who decline our service.	our commitments to Diversity, Equity, Inclusion and Belonging and reaching those who need us the most, by understanding who accesses our services, and who doesn't.	a total of 1,443 grants were given valued at £376,781 - We welcomed 633 families to our homes throughout the year for a total of 23,892 nights. The average length of stay was 18.6 nights, and the longest stay was 327 nights - Our Benefits and Welfare Advice Service answered 2,212 enquiries on a range of topics including debt, housing and benefits.
Feedback data *What do our beneficiaries think about our services? How can we learn from their experiences?*	In our surveys we ask for qualitative feedback – for example about what was good about our support, what we could have done better, how we could improve people's access to our support, and how people would rate our support. We have recently relaunched one of our surveys so we will have much more of this in future. We also review case studies from children, young people and families we support.	Feedback gives us invaluable insight into how people experience what we do, so that we can improve our services to ensure they meet people's needs and expectations, and are relevant.	**Homes from Home**: Between February 2023 and May 2025 based on 356 responses, we know that 93% rated their stay as 'excellent'.
Outcomes data *What are the*	Throughout our relationship with people, we ask them about their needs for support and how these	Outcomes data helps us to understand whether our service delivers benefits for children, young	We are routinely collecting outcomes data as part of our survey programme. We relaunched one of our surveys in June 2025 so will be

***shorter term benefits** for children, young people and their families?*

are changing. We also do surveys in which we ask people about the extent to which our support has helped them in various aspects of their lives, such as:

- Their relationships and feeling less isolated
- Managing their money
- Their emotional and mental wellbeing
- Feeling informed
- Feeling heard and understood
- Managing their day-to-day life

We have recently relaunched one of our surveys so we will have much more of this in future.

We have also recently started asking people to rate their wellbeing - using the standardised Office of National Statistics ONS4 questions, meaning that these results can be compared to a population baseline.

We are also able to make an estimation of the financial gains that families have made as a result of the welfare advice service that we offer. people and families, while we are working with them, and at the point at which we stop directly supporting them.

This data tells us where we are strongest, and we can review these outcomes at different times to look at how our service outcomes are changing.

In the future, we will be able to look at how outcomes relate to other types of data, so we can see more clearly which interventions combine into the most powerful outcomes. gathering lots more of this data in the coming months.

Our surveys are developed with young people and families.

Some recent results relating to our Homes from Home, and Welfare Advice services:

Homes from Home: Between February 2023 and May 2025 based on 356 responses, we know that:

- 87% of people who answered the survey agreed or strongly agreed that staying at the Home from Homes **helped their mental wellbeing**

- 82% of respondents agree or strongly agree staying at the Home from Homes made them **feel less isolated**

- 93% of respondents agreed or strongly agreed Home from Home service has **helped keep their family together under the same roof**

- 98% said Home from Home service has **helped them to save money**.

Welfare Advice Service: In 2024 (January to December) around 650 unique people from across the UK accessed our welfare advice service, delivered in partnership with

			Citizens Advice Bureau. Those accessing the service had a total **estimated financial gain of £1.4m**.
Impact data *What are the **long term benefits** for children, young people and their families?*	We are beginning to collect data over a longer period of time after we have stopped working with people, to understand whether the short-term outcomes described above continue into the future, and how people's wellbeing is over time. Over time, this data will help build a longer picture of our impact.	Impact data will tell us whether the benefits we deliver to our people are sustained over time. We know from our work and research that cancer and cancer treatment can have a profound impact on people's wellbeing long into the future. We want to develop our services in ways that support improved wellbeing in the longer term as well as short term.	Research published in 2024 showed that measuring wellbeing over the long-term is really important: • Young people who were treated for cancer have 36% higher levels of anxiety than the population at large, and this remains true more than six years after treatment. We are working on a project now to work out how we can collect this long-term evidence in future.

What's next? Creating a culture of learning

We must learn from the information we collect and enable others to do so as well. We know everyone working with children and young people with cancer and their families wants better information about people's experiences, so that we can all learn and adapt what we do, to bring about the North Star vision.

A strategic priority of Young Lives vs Cancer is therefore to build on the research done to date, to get better access to and do more with the wide range of user data we collect, to work with others to develop the data and insight about the experiences of children and young people with cancer, highlight the gaps, make sure it is timely, and make sure it is accessible by all those with the power to improve people's experiences.

As a first step, as well as the work outlined above to make our data more accessible, we've invested in dedicated resource to help create a comprehensive Measurement Framework for the North Star vision. This will build upon our current approach as described above. It will highlight measures of relevance to the entire system of support, acknowledge gaps in the data, and enable Young Lives vs Cancer to align our own contribution to outcomes and impact directly to the North Star. This Measurement Framework will form the backbone of our next full impact report, planned for 2026.