

10 YEAR CANCER PLAN: CALL FOR EVIDENCE



Young Lives vs Cancer submission

March 2022

Introduction

Children and Young People's Cancer is different from adult cancer because:

- It is less common
- It comes at a unique time and developmental stage of someone's life
- It has significant long-term effects
- It has unique emotional and mental health impacts
- It has a specific set of financial implications, such as travel costs to receive specialised care.

Because of this, the care and support necessary to meet the needs of this group is different from those of adults with cancer. Whilst there are some commonalities such as needing a robust and future proof workforce of specialist cancer nurses, there are many issues that are unique to this population. The following submission sets out the specific issues facing children and young people's cancer care and support needs and the cancer services needed to deliver world leading care and outcomes for young cancer patients.

The voice of children and young people with cancer and their families must be paramount in planning the future of cancer services. Young Lives vs Cancer consulted approximately 100 parents and 60 young people directly on their views on the upcoming 10 Year Cancer Plan - through online polls and conversations. In addition, the research and evidence referred to throughout this submission primarily comes from research Young Lives vs Cancer has conducted over the last 8 years with children and young people with cancer and their families.

Key Recommendations

1. A Children and Young People's Cancer Plan should be developed with input from young cancer patients and their families, the voluntary sector and health care professionals - this should form an integral part of the wider 10 Year Cancer Plan.
2. Young people and families must be supported with their travel costs to treatment to ensure access to treatment is equitable wherever you live. Funding should be ringfenced to provide this financial support which could be delivered through a dedicated fund.
3. Evidence-based mental health interventions for young cancer patients should be part of the treatment pathway and after care, and provided consistently across the UK. A collaborative sector approach (such as that outlined in the NHS Psychosocial Task and Finish Group) will help to ensure information, signposting and accessibility of support services provided by the NHS and Third Sector Organisations.
4. Age appropriate, personalised care should be core to the way young cancer patients receive services – whether they receive treatment at a specialist centre, closer to or at home. The

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support needed to deliver this care with their unique needs catered for, must be provided consistently.

5. Accessible, timely data for children and young people with cancer must be available for incidence, prevalence, routes to diagnosis, and clinical trial entry. In addition to a full range of outcome data over long periods of time.
6. Health professionals must be supported to identify children and young people's cancer through training, awareness and access to specialist professional expertise. Public facing campaigns are needed to empower young people and parents and support them to receive a timely diagnosis.
7. Joined up and single point of access follow up aftercare services are needed to deliver long term aftercare to address the long term and late effects of childhood and young adult cancer (e.g. physiotherapy and mental health support).

In addition to our evidence submitted here, we endorse the submissions of the Children and Young People's Cancer Coalition, Cancer 52, and One Cancer Voice – which we have contributed to, and the submission of the Children's Cancer & Leukaemia Group (CCLG) and Teenage Cancer Trust.

Priorities for the next 10 years of cancer services in England

In a recent poll¹ young people with cancer and parents told us the priorities for the Cancer Plan should be:

1. Getting more people diagnosed quicker
2. Improving after care support
3. Raising awareness of the signs and symptoms of cancer
4. Improving access to and experiences of cancer treatment

A number of people also responded with additional priorities areas which are discussed in more detail below. Regarding prevention and causes – the consensus was that this was not a priority as children and young people's cancer is not caused by lifestyle, environmental and other preventable factors (as with many adult cancers). Young Lives vs Cancer would also add improving data as a key priority, as delivering the above priorities is dependent on data which is currently lacking. This is discussed further below.

Delivering these priorities

Improving access to and experiences of cancer treatment

Cancer Costs

Cancer treatment places a significant financial burden on young cancer patients and their families due in part to the way services are delivered; It is right that treatment is given where it leads to the best health outcomes (often at specialist treatment centres far from home) but the financial and other impacts of this model must be addressed so that having cancer does not create and further existing economic and health disparities. Our research found that cancer can cost an additional £600 per month on items such as food, clothing and travel.² Developments in the way services are being

¹ Polls conducted March 2022 on Young Lives vs Cancer's closed facebook groups for; young people with cancer (approximately 60 respondents); parents and carers (95 respondents), and on a separate group for fathers (approximately 20 responses).

² Cancer Costs (2016) Young Lives vs Cancer (As CLIC Sargent)

delivered (for example via Ambulatory Care) can increase the financial burden on a family whilst offering many benefits³ and the support needed to deliver this care must be commissioned or provided consistently e.g., accommodation and other costs, and emotional wellbeing support for patients and carers.

Travel Costs

Travel costs are a significant challenge to access to cancer services for young cancer patients. Services are primarily delivered at specialist treatment centres often far from home. Analysis of around 7000 journeys of young cancer patients, found that young cancer patients and their families travel an average 60 miles to and from hospital for treatment, and this can cost around £180 a month on travel when treatment is at its most intense.⁴ Existing financial support available to those on the lowest incomes is not accessible to the majority of families paying these costs. As England pursues its aim to deliver ground breaking specialist treatments such as Proton Beam Therapy, safeguards are needed to reduce disparities and access barriers to those from different regions travelling for treatment. Funding to provide financial support for every young cancer patient with these costs would ensure access to treatment is equitable wherever you live. Young Lives vs Cancer has developed costings and a model which could implement this via a Young Cancer Patient Travel Fund, and would be happy to provide further details. In Scotland, this approach has recently been launched via a £5 million annual 'Family Fund' covering expenses for food, travel and overnight accommodation for young hospital patients.

"I have to travel so far for the hospital I'm at to get the best treatment. That in itself causes issues. The only other thing I can think of is expense. It's expensive being sick and nobody warns you of that".

Parent of a child with cancer

Recommendation: Young cancer patients must be supported with their travel costs - funding to provide financial support for every young cancer patient with travel costs would ensure access to treatment is equitable wherever you live. This could be administered through a dedicated Young Cancer Patient Travel Fund.

Mental Health Support

Cancer has a significant impact on the mental health of young cancer patients: our 2017 research found that 70% of young people reported depression, 90% loneliness and 90% experienced anxiety during treatment.⁵ The emotional impact of cancer on young cancer patients and their families has only been made worse by the strain of the COVID-19 pandemic – in 2020 52% of young people reported that they were not coping due to the dual strain of cancer and COVID-19 and 46% of parents felt the same way.⁶ Whilst some parents and young people report excellent emotional and psychological support from a range of services including NHS specialist provision and support by third sector workers like Young Lives vs Cancer Social Workers – access to support services can vary by treatment location.

Recommendation: Evidence-based mental health interventions for young cancer patients should be part of the treatment pathway and after care, and provided consistently across the UK. A collaborative sector approach (such as that outlined in the NHS Psychosocial Task and

³ Finch, A. *et al.* Experiences of delivering and receiving ambulatory cancer care: Community-Based Participatory Research to inform teenage and young adult cancer services. NIHR ID: ICA-CDRF-2028-04-ST2-034, IRAS ID 273131.

⁴ Are we nearly there yet? (2018) Young Lives vs Cancer (as CLIC Sargent)

⁵ Hidden Costs (2017) Young Lives vs Cancer (as CLIC Sargent)

⁶ Cancer and Coronavirus. As tough as it gets? (2020) Young Lives vs Cancer (as CLIC Sargent)

Finish Group) will help to ensure information, signposting and accessibility of support services provided by the NHS and Third Sector Organisations.

Age appropriate care and support

Having cancer as a child or young person means that support from a parent, carer or support service is even more important – navigating cancer treatment whilst also navigating puberty or key educational milestones, for example, is complex and brings additional challenges. Health care professionals at specialist centres may have more understanding of these unique needs, but some young cancer patients may have at least part of their treatment at a shared care hospital.

Recommendation: Age appropriate, personalised care should be core to the way young cancer patients receive services – whether they receive treatment at a specialist centre, closer to or at home. The support needed to deliver this care with their unique needs catered for, must be provided consistently.

Workforce

Children and young people's cancer is a highly specialised field which requires a unique skill set for some critical roles - such as histopathology, clinical and medical oncology, paediatric haemato-oncology, nursing, and dietetics. The NHS service specification outlines minimum training requirements for some roles, but this can't be achieved without adequate provision of children and young people specific education, time out for education, backfill in the workplace and funding for essential courses.

Recommendation: The Cancer Plan must recognise and support the HEE ACCEnD (Aspirant Cancer Career Education Development) programme, for implementation in each UK nation and for the workforce providing cancer care across all ages.

Improving data and translating research into practice

Lack of data and monitoring of outcomes

Limited access to timely data is a barrier to improving children and young people's cancer services. For example, lack of data on location and quality of treatment. Such information allows us to understand whether the right treatment and care has been provided for the young cancer patient. (Children and Young People's cancer services ambitions for the next 10 years, 2014). Adequate data would allow for children and young people's cancer services to compare national and international outcomes. Data for this group must be made available by 5-year age grouping for each cancer type, for incidence, prevalence, routes to diagnosis, and trial entry. In addition, a full range of outcome data over long periods of time (mortality, overall survival, event free survival, late effects and consequences of treatment by treatment type) on a population basis, not just from small cohort studies. Currently, this data is not accessible or available.

Priority and resource must be given to the analysis of children and young people's cancer data within the National Disease Registration Service so this data is available. Without wide-ranging data, it will prove difficult to improve outcomes and the experiences of young cancer patients.

Recommendation: Accessible, timely data for this group must be available for incidence, prevalence, routes to diagnosis, and clinical trial entry. In addition to a full range of outcome data over long periods of time.

Cancer Patient Experience Surveys

Often, the voice and experiences of children and young people is overlooked and there is a lack of comprehensive data available. The Under 16 Cancer Patient Experience Survey is key in allowing us to understand the experiences of children and their families, providing insight into the strengths and weaknesses of cancer services. Such surveys are a step in the right direction allowing us to recognise the unique challenges that children and their families face during diagnosis and treatment.

We would very much welcome the implementation of this survey in each nation in the UK, drawing upon the successful model in England as an example. Response and engagement rates from young people and minoritised groups in the adult Cancer Patient Experience Survey tends to be low.

Recommendation: A tailored approach should be taken when collecting data for teenagers and young adults to obtain a more accurate understanding of their experiences when accessing cancer services. Continued and meaningful patient involvement is vital in the planning and delivery of research and data collection as well as output dissemination.

Clinical Trials

It is important that children and young people have access to innovative treatments to improve survival rates, side effects and long-term health outcomes.

Recommendation: The government must continue to support children and young people to take part in clinical trials through accessible information and engagement strategies so that participation among young people can increase to 50% by 2025, as per the NHS Long Term Plan for England.

Raising awareness of the signs and symptoms of cancer and getting more people diagnosed quicker

Cancer in children and young people is less common than cancer in the adult population, which makes it difficult for GPs to identify suspected cancer. GPs also face a number of challenges such as limited training and awareness, time pressures and the nature of the referral pathway. Our research found that one third of GPs reported insufficient opportunities to gain experience in the care of children and young people during their initial training was one of the top barriers to identifying cancer in children and young people. More than half (53%) said continuing professional development schemes on cancer in children and young people would be beneficial in providing them with additional support or advice on diagnosis. As a result, diagnosis can be a mixed experience - around half of young people (52%) and almost half of parents (49%) surveyed had visited their GP at least three times before their cancer was diagnosed.⁷

We welcome NHSE plans to extend public cancer awareness raising to the rare and less common cancers and call for the government to support the Child Cancer Smart Campaign being developed by the Children's Cancer & Leukaemia Group (CCLG). This will include raising public and professionals' awareness to help debunk the myth that childhood cancer is rare, but rather that it is less common than adult cancers. Awareness campaigns such as Teenage Cancer Trust's #BestToCheck can also play a vital role in empowering young people and parents to discuss cancer symptoms with care professionals. It is also vital that there is ongoing training and support for health care professionals. Access to expertise is key to ensuring that they are able to diagnosis and refer patients for diagnostic testing in the timeliest way which maintains trust and good relationships with parents and young cancer patients.

"GP's need to have training on recognising symptoms early on instead of dismissing them...They almost seem to think because a person is young that it can't be cancer yet hundreds are diagnosed each day".

Young person with cancer

Recommendation: Health professionals must be supported to identify children and young people's cancer through training, awareness and access to specialist professional

⁷ The best chance from the start (2016) Young Lives vs Cancer (As CLIC Sargent)

expertise. Public facing campaigns are needed to empower young people and parents and support them to receive a timely diagnosis.

Improving after-care and support services for cancer patients and their families

Cancer treatment can have a long-term impact on both the physical and mental health of a young person. In the report of the All-Party Parliamentary Group for Children, Teenagers and Young Adults with Cancer, 73% of parents and young people said that they felt that there was not enough being done to ensure access to post-treatment support.⁸

There are a range of long-term issues at play for this group who have had a life changing health condition at a sensitive developmental time. This includes emotional impact; fertility issues, disability and other health conditions; and impact on education and employment.

Physical and mental health support should be included as a key part of their diagnosis, treatment, follow-up plan and recovery package. A clear point of access is needed into non-cancer follow-up and long-term services such as mental health support and physiotherapy. Young people have reported that this is variable depending on local services, particularly as time elapses from their initial treatment.

“Why can't there be dedicated rehab centres for all young people with any illness? I really struggled to get into specialist services until I was 18. This year is 4 years since my diagnosis and I am still under several specialists for my side effects”.

Young person with cancer

Recommendation: Joined up and single point of access follow-up aftercare services are needed to deliver long term aftercare to address the long term and late effects of childhood and young adult cancer (e.g. physiotherapy and mental health support).

Conclusion

The practical, emotional and age specific burdens that treatment places on young cancer patients must be accounted for to deliver truly world leading cancer care which is accessible to all regardless of income, age or circumstance. The future of cancer services must deliver evidenced, age-appropriate support and care, working collaboratively with the voluntary sector to consistently deliver the emotional, practical and financial support needed.

About Young Lives vs Cancer

We fight tirelessly for young cancer patients – individually, locally and nationally. Every year in the UK over 4,000 children and young people under 25 are diagnosed with cancer. That means every day 12 children and young people hear the news they have cancer. Nine children and young people die from cancer every week in the UK - Cancer is the biggest killer of children and young people by disease in the UK. When cancer strikes young lives we help families limit the damage cancer causes beyond their health. We do this by providing social workers, financial grants and via our Homes from Home.

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⁸ Listen Up! (2018) All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer