

NATIONAL CANCER PLAN FOR ENGLAND

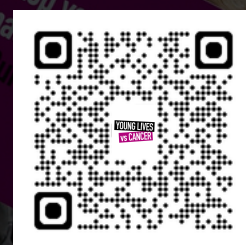
YOUNG LIVES
vs CANCER

How to have your say.

UK Government have opened a call for evidence where you can share your priorities for the upcoming Cancer Plan for England.

Here's how to share your thoughts, experiences and opinions on what the plan should include to make sure it meets all the needs of children and young people with cancer.

1. Go to the UK Government call for evidence webpage
2. Choose whether you are sharing your personal or professional views
3. Fill in the 'about you' section
4. The next seven sections will ask you about your priorities for the Cancer Plan. Use the 'Other' option to share longer messages.



If you're not sure what to say for each section, we've put together this guide to help you as you go.

There are seven main sections sections in the call for evidence. Each section starts with a multiple choice question and then leaves space for longer answers. Our guide can help you to make it clear in your answers that the National Cancer Plan must be more than medical for children and young people and their families - it must deliver practical, emotional and financial support, alongside world class medical care.

Prevention

Using the “other” response option, you could say that most cancers in children and young people can’t be prevented by focusing on factors like alcohol and smoking. It is important that focusing on prevention for adult cancers doesn’t mean that children and young people are forgotten.

For young cancer patients, the Plan must include actions to improve earlier and faster diagnosis, including reducing how many times they need to visit their GP before being diagnosed – which is more than for adults.

Improving signs and symptoms awareness for childhood cancers amongst healthcare professionals, and having effective referral pathways in place, are essential. Cancer in children and young people can often be dismissed or mistaken for other conditions, delaying diagnosis. Research could be done on screening programmes for children and young people.

Early Diagnosis

Because of the reasons above, we think the three most important things in this section for children and young people with cancer would be:

- Support timely and effective referrals from primary care (for example, GPs)
- Improve symptom awareness, address barriers to seeking help and encourage a timely response to symptoms
- Increase support for research and innovation

In the “explain your answer” box, you could use some of the examples we’ve included for “prevention” above which also apply to “early diagnosis”.

Early (and fast) is really important for children and young people with cancer because cancer in this group can be more aggressive and faster growing, and being diagnosed quickly means they can get the treatment they need sooner, which often improves their overall outcomes.

Treatment

Three important things from this section which could be key for children and young people with cancer are:

- Increase the availability of physical and mental health interventions before and during cancer treatment
- Improve communication with patients, ensuring they have all the information they need
- Improve the flow and use of data to identify and address inconsistencies in care

In the “explain your answer” box, you could say that emotional and mental health support is also important, alongside clinical care. Because the emotional impacts of having cancer start when you’re diagnosed, support for this should be available from diagnosis, throughout treatment and after treatment too. This support should be for children and young people with cancer and their families too.

Many young cancer patients and their families say they would have liked more information about their diagnosis and treatment. This should be addressed because having this information means they can better understand what is happening and make informed decisions about their care.



Living with and beyond cancer

This section is probably the most important to Young Lives vs Cancer because it focused on psychosocial support. The top three could be:

- Improve the emotional, mental health and practical support for patients, as well as their partners, family members, children and carers
- Offer targeted support for specific groups, such as ethnic minority cancer patients, children and bereaved relatives
- Provide more comprehensive, integrated and personalised support after an individual receives a cancer diagnosis and (if applicable) after treatment

In the “explain your answer” box, you could say that psychosocial support is just as important as clinical care for children and young people, so must be a focus of the National Cancer Plan. Targeted, age-appropriate support for children and young people is essential because their needs and experiences are different to older adults. They need integrated access to psychosocial support alongside their clinical care.

Children and young people travel to specialist centres for their treatment which costs an average of £250 every month which is a big financial strain and can impact someone's ability to access their care. A Young Cancer Patient Travel Fund is needed to reduce the financial impacts of cancer and to ensure no child or young person misses or delays their treatment because of the cost of travelling to the hospital.

There are many additional costs that come with cancer, averaging around £700 every month so it's important that changes are also made to welfare benefits to make these quicker and easier to access for children and young people with cancer and their families.

Emotional support should be available for young cancer patients and their families from day one of diagnosis, throughout treatment, and after treatments ends.

Research and Innovation

Young Lives vs Cancer aren't the experts in this area, but we've worked with the Children's Cancer and Leukaemia Group (CCLG) on our Children and Young People's Cancer Plan, which includes points on "research and innovation". Some important points in this section could be:

- Improve patient access to clinical trials
- Improve the data available to conduct research
- Increase research on rarer and less common cancers

In the "explain your answer" box, you could say that it's important that children and young people are able to access clinical trials. This includes there being trials available for them (and not just for adults)

Research should cover the types of cancers and priorities that children and young people have and experience, so research can better benefit young cancer patients. The types of cancers that impact children and young people are also those which are often classed as "rare and less common", so focusing on these cancers would help young cancer patients.

Improving research and innovation would be made easier by improvements in the data available for children and young people – currently there isn't much routine cancer registry data for children and young people.

Inequalities

Three important things from this section which could be key for children and young people with cancer are:

- Raising awareness of the signs and symptoms of cancer, reducing barriers and supporting timely response to symptoms
- Improving and achieving a more consistent experience across cancer referral, diagnosis, treatment and beyond
- Improving the aftercare support for cancer patients

In the "explain your answer" box, you could say that children and young people experience inequalities because of their age, the types of cancers they get, and the specialist services they access. This includes going to their GP more times than adults before being diagnosed, so improving awareness of signs and symptoms and helping healthcare professionals respond to symptoms is important.

Children and young people with cancer travel twice as far and spend twice as much to get to their treatment and care than adults. They spend an average of £250 every month just on travel, which is a big financial strain, and can impact someone's ability to access their care.

Making sure that care and support is age-appropriate to children and young people's needs is important, as they have a different experience because of their age and stage in life. This needs to include access to psychosocial support for the practical, financial and emotional impacts of cancer – both during and after treatment. The impacts of cancer don't stop when treatment stops, so neither should the support and care children and young people need.

Priorities for the national cancer plan

From the list provided, the three most important priorities we think the Plan should address for children and young people are:

- Earlier diagnosis of cancer
- Improving patient experience across cancer referral, diagnosis, treatment and beyond
- Reducing inequalities in cancer incidence, diagnosis and treatment

In the “explain your answer” box, you could say that it is important that children and young people are diagnosed quickly and their symptoms are spotted quickly so they can get the treatment they need as soon as possible.

It is important that psychosocial (practical, emotional and financial) needs are considered as part of improving patient experience, and that support for these is available from day one of diagnosis all the way beyond when treatment has ended.

Children and young people with cancer have experiences that are different to those of older adults. They experience inequalities which need a bespoke approach and this should be a focus of the National Cancer Plan.

**Thank you. Together, we are making
change happen for children and young
people with cancer.**

If you have any questions or need any more information to help you fill out the call for evidence, please get in touch with the Young Lives vs Cancer Policy and Influencing Team campaigns@younglivesvscancer.org.uk.