

### **Question 1:**

**The core proposals in the green paper are:**

- **All schools and colleges will be incentivised and supported to identify and train a Designated Senior Lead for Mental Health who will oversee the approach to mental health and wellbeing**
- **Mental Health Support Teams will be set up to locally address the needs of children and young people with mild to moderate mental health issues, they will work with schools and colleges link with more specialist NHS services**
- **Piloting reduced waiting times for NHS services for those children and young people who need specialist help.**

**Do you think these core proposals have the right balance of emphasis across a) schools and colleges and b) NHS specialist children and young people's mental health services?**

Teenage Cancer Trust exists to ensure that no young person has to go through cancer alone. Seven young people are diagnosed with cancer every day in the UK. We're the only charity dedicated to providing specialist care and support when they need it most. We've built world-class specialist facilities in 28 hospitals across the UK, providing a home away from home for young people while they receive treatment. We also fund specialist nurses and youth support co-ordinators (YSCs) to support the young people in these units. They've been specially trained to understand what it's like to have cancer when you're young, giving support and helping young people to feel less isolated.

As a result, we understand the very specific mental health needs that can accompany a young person's diagnosis, treatment and post-care. Teenage Cancer Trust's 'What really matters to young people with cancer' (2016) report outlines that for young people, cancer brought 'profound shifts in their personalities and psychological outlooks'. Worry about physical appearance, loneliness and anxiety were all highlighted as having a lasting effect on their self-esteem.

Similarly, in Teenage Cancer Trust's 'Young Voices' (2012) report, one patient highlights particularly, the 'mental scarring' of delayed diagnosis.

Teenage Cancer Trust's General Survey 2017, delivered at our 'Find Your Sense of Tumour' conference showed 81% of respondents used Teenage Cancer Trust Youth Support Co-ordinators to speak about their feelings, with 71% talking about worries/stress (the joint first and third most common responses respectively).

There is a clear link between the physical aspect of cancer in young people, and poorer mental health outcomes. Whilst Mental Health Support Teams could be a positive vehicle for identifying and referring emerging mental health issues in schools, the Government must take into account that many young people with cancer will not be attending school due to their treatment. They should consider how to better support young people with cancer throughout their journey with their specific mental health needs.

**Question 4: Do you know of any examples of areas we can learn from, where they already work in a similar way to the proposal for Mental Health Support Teams?**

Whilst it is positive to see the Green Paper consider economic and social factors such as Adverse Childhood Experiences, gang culture and sexuality in the case for action on young people's mental health, Teenage Cancer Trust is disappointed that the impact of physical health conditions such as cancer are not considered. CLIC Sargent's 'Hidden Costs' (2017) survey of young cancer patients

showed 70% had experienced depression, 90% experienced anxiety, and 42% experienced panic attacks during treatment. It is clear that those young people managing a cancer diagnosis are experiencing mental ill health at a significantly higher rate than the national average.

Teenage Cancer Trust employs Youth Support Coordinators (YSCs) across the UK to support the wider needs of young people during and after treatment – including their emotional wellbeing. In an Opinion Leaders research study (2018) for Teenage Cancer Trust about our Impact and Outcomes, the research revealed that the role the Youth Support coordinators played, was vital in the cancer journey of teens and young adults. Here 89% of young people commented that their YSC was important during treatment, with 97% going on to say that they were important after treatment.

An example of their impact is where physical changes to young people's bodies, during and following their treatment, impacts on their self-esteem. YSCs specifically made an effort to discuss this topic with young people and, last year, in an average month, 68% were able to do so.

Every young person with cancer should be able to access the mental health support they need to manage treatment, and get back on track afterwards. Teenage Cancer Trust's YSCs are an example of how effective such dedicated support can work, but we are concerned that many young people with cancer can't access such support, and that neither is it a substitute for dedicated professional mental health support. We also provide programmes of ongoing support to young people who've had cancer, for instance through our Way Forward programme, we are keen to share learning from our YSCs and support services with the Government when taking these proposals forward.

NHS mental health services could also have a stronger presence within schools, for example drop in sessions for pupils with concerns. Also apps such as Headspace and complementary therapy teams have proven popular with young people in our services but are not available nationwide.

When considering programmes for transforming young people's mental health, the Government should consider the specific mental health needs of young people with cancer and how programmes such as our Youth Support Coordinators improve their wellbeing, as well as how the mental health offering for these young people could be expanded.

### **Question 9: How can we include the views of children and young people in the development of Mental Health Support Teams?**

Teenage Cancer Trust is committed to putting the voice of young people with cancer at the heart of all its work. We engage with young people in a range of ways in order to ensure their views are conveyed throughout our decision making. Methods of engagement can include commissioning agencies to conduct qualitative research, surveying service users, consultation at annual conferences, and face to face input about their patient experience.

In Teenage Cancer Trust's 'What really matters to young people with cancer' (2016) report, a number of repeated priorities for this group emerged, many of which directly relate to their mental wellbeing. The research identified these particular themes (amongst others) as: support being given to them in an age appropriate way, to help them to feel more comfortable with what was going on; that the physical effects of cancer on appearance had a long term effect on self-esteem; feeling in control of their cancer journey helped prevent young people being overwhelmed, and; tailored support to find their 'new normal' during and after treatment helped them to get back on track.

Teenage Cancer Trust is particularly aware of the consistent benefit that young people with cancer report in being able to share with others who have had similar experiences. Teenage Cancer Trust runs the 'Way Forward' programme, which aims to increase confidence to help effectively manage life after cancer and its treatment, and along with our 'Find Your Sense of Tumour' conference allows young people the opportunity to make friends and share with others who have been through similar experiences. In an Opinion Leaders research study (2018) for Teenage Cancer Trust about our Impact and Outcomes, the research found that, six weeks on from the event, 86% of young people were still in touch with other young people they had met at The Way Forward.

As the Government considers Mental Health Support teams as a form of early intervention, they should not forget the specific needs that young people with cancer have. Mental health support teams in schools are unlikely to be an effective mechanism for helping these young people. It is also important to remember that not all young people experiencing mental health issues will want to engage in consultation, but by involving youth workers, nurses and doctors there will be support and advocacy to ensure young people's views and experiences are considered. In order to help address their mental health needs, the Government should consider how it can better meet the repeated priorities that young people with cancer have made clear to Teenage Cancer Trust.

Teenage Cancer Trust surveyed young people with cancer ahead of this submission, asking them what mental health support would make a difference to them and others. Some of the views included:

'Knowing the recovery process is not just physical. And when the scars are fully healed and you are back at work/uni if there was a break, you take at least twice as long to be mentally and emotionally okay.'

'[Giving] young people [a] place to vent their grief, sorrow and anger towards being diagnosed and their worries that they may not feel comfortable telling Doctors or CNS'

'Counselling available right away and regularly'

It was clear from the survey too, that young people felt that any mental health support the Government explores, should be in close consultation with young people. One young person said 'there is no point creating something if that's not going to help young people in the way young people need. Take our views and base the new support on it'.

**Question 19: Please provide any evidence you have of the impact of interventions for children with mild to moderate mental health needs, as could be delivered by the Mental Health Support Teams. We are interested both in evidence of impact on mental health and also on wider outcomes such as education, employment, physical health etc.**

Teenage Cancer Trust can demonstrate a significant impact in supporting young cancer patients in line with what most matters to them. The 'What really matters to young people with cancer' (2016) report considers the gaps in what matters most to young cancer patients against how well supported they feel along their journey. Pulse maps illustrating the data show significant reductions, and multiple incidences of no gap between the trajectories (the experience is best when the gap is the smallest), for young people who were treated in a Teenage Cancer Trust unit, compared to when they were not.

Being treated in a specialist unit that provides for their specific needs, with dedicated staff looking out for their welfare, made young cancer patients considerably more likely to feel more supported throughout their cancer journey. A key intervention for young people with cancer is ensuring

referrals for mental health support are made as early as possible, at diagnosis, throughout treatment and at the end of treatment. Making this a part of all young people's diagnoses would help to ensure no young person misses out on support and would help to normalise and remove any stigma in receiving it. Therapeutic interventions such as cognitive behavioural therapy, counselling, motivational interviewing and family support can all be beneficial for young people with cancer who are experiencing mental health issues.

Many young people with cancer report having body image worries when undergoing treatment and experiencing changes such as hair loss or a change in weight. Given that the Government's approach to transforming children and young people's mental health has placed specific emphasis on eating disorders, they should consider the specific effects that a cancer diagnosis can have on creating or exacerbating body image issues. This can make young people feel out of control and affect their confidence. Charities such as Look Good Feel Better have been identified as providing a successful intervention in helping with body image worries whilst also providing an opportunity for peer support during their workshops.

Areas where the gap was smallest included how they were communicated to about their treatment, understanding and mitigating the changes to their bodies and circumstances, and being able to make friends after treatment.

Teenage Cancer Trust's Way Forward programme helps 18-29 year olds who've finished treatment to get back on track, and come and receive helpful guidance for their life after cancer.

The event can cover a range of important and relevant themes, including: fertility, late effects, education and employment, relationships, body image and fatigue management. In an Opinion Leaders research study (2018) for Teenage Cancer Trust about our Impact and Outcomes 93% said they felt better equipped to manage their health and well-being in the future as a result of attending the Way Forward event.

Ahead of this submission, Teenage Cancer Trust surveyed a range of healthcare professionals. Some of the responses about interventions that had a positive effect on the mental health of young people with cancer included:

'Specialist support nurses, CLIC Sargent Social workers, Teenage Cancer Trust Youth Support Coordinators, Physiotherapists, Occupational Therapists have all had a positive impact and each have in their own way been a lifeline in some form along the young person's journey. Complementary Therapies are of benefit also'

'Through my role as a Teenage Cancer Trust Youth Support Coordinator, the majority of my interventions aim to improve mental health and wellbeing; whether this is through activities, social events, liaising with schools and colleges in regards to workload and the young person's ability to engage whilst undergoing treatment'

'I see a world of a difference in the young people I work with who attend the Ellen Macarthur sailing trips. I think there is a need to [*sic*] career advisors post treatment. I've noticed that young people can lose their sense of purpose, become unhappy returning to how things were but aren't sure how to move forward'

The Government, NHS England and Public Health England should consider how Teenage Cancer Trust supports the specific needs of young people with cancer and the benefit this has on their mental health and wellbeing in the short term and the long term.