

Advancing our health: prevention in the 2020s - October 2019

(1) Which health and social care policies should be reviewed to improve the health of people living in poorer communities, or excluded groups?

Recent research from Teenage Cancer Trust and Public Health England¹ reported key findings on incidence, mortality and survival rates for teenage and young adult cancer, including findings on deprivation and geography. The report found that there are statistically significant variations in the incidence and survival rates of cancer in 13 to 24 year olds, whether considered by geography and levels of deprivation.

The report showed teenagers and young adults with cancer living in the least deprived areas had higher five-year survival rates than those in the most deprived areas. There were also significant variations in incidence by diagnostic group when grouped by level of deprivation. For example, the incidence rate for skin cancers was significantly higher in the two least deprived quintiles when compared to the two most deprived quintiles.

This report was the first of its kind looking at this specific age group, 13 to 24 year olds, so conclusions as to why inequalities exist cannot yet be made. It is therefore crucial that the Department of Health and Social Care prioritise funding research into teenage and young adult cancer, focussing on inequalities and the impact this can have, and considering ways that this can be addressed.

(4) How else can we help people reach and stay at a healthier weight

Obesity is the second biggest preventable cause of cancer in the UK.² Obesity is also an issue in children and young people, which can lead to adverse effects on health as an adult. It is vital young people know how to maintain a healthy weight and stay physically active, in order to reduce their risk of developing cancer in adulthood.

In 2017, 30% of children aged 2 to 15 in England were overweight or obese.³ There is no link between obesity and cancer in childhood, but a healthy body weight is important for children and young adults, as children who are obese are around 5 times more likely to grow into adults who are obese.⁴

¹ Public Health England and Teenage Cancer Trust (2018) 13-24 year olds with cancer in England: Incidence, mortality and survival

² www.cancerresearchuk.org/about-cancer/causes-of-cancer/obesity-weight-and-cancer/does-obesity-cause-cancer

³ NHS Digital (2018), Health Survey for England 2017, <https://files.digital.nhs.uk/5B/B1297D/HSE%20report%20summary.pdf>

⁴ www.cancerresearchuk.org/about-cancer/causes-of-cancer/obesity-weight-and-cancer/does-obesity-cause-cancer#Obesity0

Raising awareness for how to live a healthy lifestyle, including staying active and maintaining a healthy diet for children, teenagers and young adults could create a healthier generation, and reduce the number of people developing cancer in the future.

(7) There are many factors affecting people’s mental health. How can we support the things that are good for mental health and prevent the things that are bad for mental health, in addition to the mental health actions in the green paper?

There are specific mental health needs that can accompany a young person’s cancer diagnosis and treatment. These teenagers and young adults with cancer should be supported by an ongoing age-appropriate holistic needs assessment to help support their psychological, social and emotional needs.

The challenges that come with adolescence, experienced by a young person without cancer, are considerable. They can impact physical, cognitive, psychosocial and social changes. For a young person with cancer who will have to manage all of this on top of a cancer diagnosis, this can be even more disruptive to the young person’s development and can lead to psychological distress.⁵

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’.⁶ Similarly, 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.⁷ This detrimental psychological impact can continue into adulthood if not addressed.⁸

Having a holistic needs assessment specifically for teenagers and young adults enables care teams to understand the needs of the young person and their family on an ongoing basis, and direct from the young people themselves. This helps to ensure they receive the support and information they need throughout diagnosis, treatment and beyond.

Teenage Cancer Trust is currently rolling out the ‘Integrated Assessment Map (IAM) Portal’ to teenage and young adult cancer services across the country. This is an age specific online needs self-assessment which provides a structure to support professionals and young people in holistically assessing needs for information and support at any point in their cancer journey. It is designed to look at the impact of, and adjustment to, their cancer and its treatment within a bio-psycho-educational-vocational framework i.e. what does having cancer and its treatment mean for this young person and their support network at this point in time.

The IAM Portal should be endorsed by NHS England as the single teenage and young adult Holistic Needs Assessment to be used across all teenage and young adult cancer networks to help improve the psychological, social and emotional support of young people with cancer.

⁵ https://www.teenagecancertrust.org/sites/default/files/BlueprintOfCare_2ndEdition.pdf

⁶ ‘What really matters to young people with cancer’ (2016)

⁷ ‘Hidden Costs’ (2017)

⁸ https://www.teenagecancertrust.org/sites/default/files/BlueprintOfCare_2ndEdition.pdf

(8) Have you got examples or ideas about using technology to prevent mental ill-health, and promote good mental health and wellbeing?

As already outlined, teenage and young adult cancer comes with a specific set of mental health needs. To improve the mental health impact of a cancer diagnosis on a teenager or young adult, young people must be supported by an age-appropriate holistic needs assessment.

Teenage Cancer Trust's IAM Portal is a tested holistic needs assessment specifically designed for teenagers and young adults with cancer. It is a tool that helps young people be active in their own care. It also provides the young person with a way of communicating with the team looking after them.

The recently updated NHS England Service Specifications for teenagers and young adults with cancer set out requirements for all teenage and young adult Operational Delivery Networks to approve a single teenage and young adult specific holistic needs assessment.⁹ Teenage Cancer Trust's IAM Portal should be the go-to needs assessment for all services working with teenagers and young adults. NHS England should work with Teenage Cancer Trust to endorse the IAM Portal as the single teenage and young adult Holistic Needs Assessment to be used across these networks.

(17) What are the top 3 things you'd like to see covered in a future strategy on sexual and reproductive health?

HPV

There is currently a generation of boys and men who are not being offered the HPV vaccination. This puts them at risk of contracting HPV, and therefore developing HPV related cancers – something that can be prevented through extending the HPV programme and offering more boys the opportunity to access this vaccine for free.

We were pleased to see the recent extension to the HPV vaccination programme, offering all boys aged 12 - 13 in England, Wales and Northern Ireland, and all boys aged 11 – 12 in Scotland the HPV vaccine from September 2019. This is an important step forward to help protect more people against cancers related to HPV, whatever your gender.

We were disappointed that despite launching this programme, the vaccine will not be available to boys who are older than these ages.

In 2008, the HPV vaccination programme was introduced to girls aged 12 and 13 across the UK, to reduce future cervical cancer cases - a cancer largely caused by HPV. Girls who miss the vaccine, or decide to have it later in life can receive the vaccine for free on the NHS until they are 25. At the start of this programme there was also a catch-up scheme for girls born between 1991 and 1995 (13 to 17 year olds), allowing this age group to access the vaccine for free on the NHS.

This is not the same for boys, as only boys who are eligible for the vaccine in this school year and below can have the catch-up service until they are 25. Boys who are older than this are not eligible to ask for the jab on the NHS. Reasons given for this appear to be cost cutting measures that largely ignore the fact that the risks of boys contracting HPV, and potentially cancer, are substantial.

⁹ <https://www.engage.england.nhs.uk/consultation/teenager-and-young-adults-cancer-services/>

HPV is most often, but not always, spread through close skin-to-skin contact, like sexual activity. It has been assumed that because girls have been able to receive the vaccine since 2008, a catch-up programme for boys is not required as boys will have reasonable levels of 'herd immunity' i.e. if girls have been vaccinated from HPV, they will not pass the virus on to boys, so boys are less likely to contract HPV. However, herd protection is not full protection. It does not protect boys who have sex with girls who have not been vaccinated, which in the UK currently stands at approximately 16-17% of girls, or girls who are from outside the UK, such as France where the vaccination uptake stands at just 21.4%.

Boys who do not receive the HPV vaccine are at a higher risk of contracting HPV, and therefore HPV related cancers. This includes cancers of the anus, penis, head and neck. Each year in the UK, HPV causes approximately 1,400 cases of head and neck cancer, 350 penile cancers, and nearly 400 cases of anal cancers.¹⁰

It is concerning that more than a million boys¹¹ and young men are set to miss out on the HPV vaccination. Teenage Cancer Trust would like the Department for Health and Social Care to make provision for all boys up to the age of 25 to be able to request free catch up vaccines from their GP or a clinic.

Fertility and cancer

In some cases treatment for cancer can affect young people's fertility - approximately 15% of patients have a high risk of future fertility problems because of it.¹² Despite this, young people often experience difficulties accessing fertility services or receiving vital information about the impact their treatment may have on their bodies. A Teenage Cancer Trust survey found that 29% of young people who were treated for cancer did not have a discussion about their fertility, and 44% of young people who did have a discussion about their fertility were not satisfied with it.¹³

Young people with cancer must be given all the information about how their treatment could affect them so that they can make fully informed decisions. Best practice says that teenagers and young adults should be given information regarding risk and there should be a discussion about the options available for fertility preservation – but we know that often, this is not happening.

The recent teenage and young adult Service Specifications outline a requirement for the teenage and young adult multidisciplinary team to consider fertility preservation services for each young person if they could be affected by their treatment. Each young adult preparing for treatment that is likely to result in fertility problems must be offered cryopreservation and have access to fertility services in accordance with NICE Quality Standard.¹⁴

Young people with cancer deserve to be given all the available information in order to have a full understanding of their prognosis and how their treatment might affect them. Teenage Cancer Trust would like every young person to be talked to about their fertility options and how their prognosis may or may not affect that. These conversations should take place regardless of whether the treatment plan involves a treatment that will affect their fertility. This will ensure all young people have a full understanding of their prognosis and what to expect from their treatment.

¹⁰ <https://www.tht.org.uk/our-work/our-campaigns/hpv-vaccine>

¹¹ <https://www.gov.uk/government/collections/statistics-school-and-pupil-numbers>

¹² NICE commissioning guidance for CYP with cancer 2014

¹³ Teenage Cancer Trust General Survey 2018

¹⁴ www.nice.org.uk/guidance/cg156/chapter/Recommendations#people-with-cancer-who-wish-to-preserve-fertility

Sexual health and cancer

Young cancer patients must be informed about how cancer treatment can affect sexual activity, including information on sexual health and protection.

In the first few days following chemotherapy, chemicals can be passed on to partners through semen or vaginal fluid, from the chemotherapy, if protection such as a condom is not used.¹⁵ Protection is also important for young cancer patients as if a young person with cancer gets pregnant while on treatment, the chemotherapy drugs can harm the babies development.¹⁶

It is vital teenagers and young adults with cancer are given the correct information on how cancer treatment can impact their bodies, fertility, and sexual health. Teenage Cancer Trust would like every young person with cancer to be talked to about the impact treatment can have on their body, including how this can affect sexual activity.

(18) What other areas (in addition to those set out in this green paper) would you like future government policy on prevention to cover?

The cancers common in young people are rare, can be harder to diagnose and most of these cancers are not preventable through lifestyle choices. However, considering how to improve early diagnosis in this age group would play a vital role in improving the survival, experience and recovery of teenagers and young adults with cancer.

Every year in England, 2397 young people are diagnosed with cancer, with cancer being the biggest killer of young people by disease. It is crucial that early diagnosis is improved in this age group, as patients diagnosed at an early stage are more likely to survive cancer.¹⁷

Teenage Cancer Trust is concerned however by the barriers facing young people with cancer around early diagnosis. In a survey of young people with cancer, 73% did not think enough was being done to improve experience of diagnosis.¹⁸

The 2018 Cancer Patient Experience Survey¹⁹ showed that still, many young people will experience multiple visits to their GP before receiving a diagnosis. When asked how often patients visited their GP before diagnosis, 16 – 24 year olds reported the highest percentages compared with other age groups for answers ‘I saw my GP 3 or 4 times’ and ‘I saw my GP 5 or more times’.

It is important GPs and medical professionals become more aware of cancer in young people in order to reduce delayed routes to diagnosis. In a survey carried out by the All-Party Parliamentary Group on Children, Teenagers and Young Adults with cancer, 53% of respondents suggested better training for GPs on cancer in children and young people would be the biggest single improvement that could be made to experiences of diagnosis.²⁰

¹⁵ www.macmillan.org.uk/information-and-support/treating/chemotherapy/side-effects-of-chemotherapy/effects-on-sex-life.html#17428

¹⁶ www.macmillan.org.uk/information-and-support/treating/chemotherapy/side-effects-of-chemotherapy/effects-on-sex-life.html#17428

¹⁷ Cancer Research UK 2018 Cancer in the UK 2018

¹⁸ [Listen Up! What matters to young cancer patients 2018](#)

¹⁹ <http://www.ncpes.co.uk/reports/2018-reports/national-reports-2018>

²⁰ [Listen Up! What matters to young cancer patients 2018](#)

Teenage Cancer Trust understands that cancer is rare in young people, with seven young people being diagnosed with cancer every day in the UK. Some GPs may only see one or two cases throughout their career, which means suspicion of cancer in young people is low. More must be done to help everybody, including GPs and other medical professionals understand cancer in teenagers and young adults better.

Alongside this, awareness of the signs and symptoms of cancer in young people is low. Herbert et al (2018) showed that some cancers that are prevalent in young people can have longer periods between spotting the sign to help seeking. Young people might spot the more definitive symptoms, such as a skin lesion but might not then necessarily associate them with cancer.²¹ Raising awareness publicly for rarer cancers, and their signs and symptoms, could lead to more people being diagnosed earlier, including young people.

Teenage Cancer Trust would like to see a specific public awareness campaign for rare and less common cancers, such as those experienced by young people. Equipping young people with vital information on the signs and symptoms of cancer through public awareness, and ensuring they are empowered to visit the GP when these symptoms occur could help improve the early diagnosis of cancer and save lives.

²¹ Herbert et al (2018) - Diagnostic timeliness in adolescents and young adults with cancer: a cross-sectional analysis of the BRIGHTLIGHT cohort