

# LISTEN UP!

## WHAT MATTERS TO YOUNG CANCER PATIENTS

All Party Parliamentary Group on Children,  
Teenagers and Young Adults with Cancer  
Inquiry into Patient Experience – July 2018

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This report was compiled by CLIC Sargent and Teenage Cancer Trust, who provide joint-secretariat services to the All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer.



All Party Parliamentary Group  
**ON CHILDREN, TEENAGERS &  
YOUNG ADULTS WITH CANCER**

## THE ALL PARTY PARLIAMENTARY GROUP ON CHILDREN, TEENAGERS AND YOUNG ADULTS WITH CANCER (APPG CTYAC)

The All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer (APPG CTYAC) exists to raise awareness of the issues affecting children, teenagers and young adults with cancer and their families in Parliament.

### The group aims to:

- Scrutinise, and make recommendations where appropriate, on the effectiveness of the system supporting young cancer patients throughout their experience of cancer
- Influence government policy to reflect the needs of children, teenagers and young adults with cancer;
- Provide a forum for discussion in Parliament of the key issues affecting children and young people with cancer
- Operate as a platform to champion the voices of young cancer patients and their families to ensure their experiences are represented to Parliament and government
- Bring together and engage with relevant stakeholders supporting young cancer patients and their families.

The APPG is supported in partnership by CLIC Sargent and Teenage Cancer Trust, who provide joint-secretariat services to the Group.

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Every year in the UK over 4,000 children and young people under 25 are diagnosed with cancer. CLIC Sargent is the UK's leading cancer charity for children, young people and their families. We fight tirelessly for young cancer patients – individually, locally and nationally. When cancer strikes young lives CLIC Sargent helps families limit the damage cancer causes beyond their health. We do this by providing nurses, social workers, financial grants and via our Homes from Home. Last year we provided services to 7,200 young cancer patients and their families, including providing over £1m of financial grants.



#### TEENAGE CANCER TRUST



Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life for 13- to 24-year-olds with cancer. We help the seven young people who are diagnosed with cancer every day,<sup>1</sup> supporting them throughout treatment and beyond. We fund specialist units in NHS hospitals and provide dedicated staff, including specialist nurses and Youth Support Coordinators. We now have 28 units across the UK and fund over 75 specialist staff posts.

We also educate young people about the signs of cancer, seeking to increase their knowledge and to significantly improve their diagnosis experience. We are currently providing our Education & Awareness presentations to 25% of all secondary schools in the UK.



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- Katie Young and Tim Sadler for sharing their experiences and for being panellists for the Inquiry
- The individuals who gave oral evidence as part of the Inquiry (full list can be found in the Appendix)
- All the Parliamentarians who contributed their time, insight and expertise by participating in the Inquiry as panellists (full list can be found in the Appendix)
- Officers of the APPG for their time and input
- The Policy, Communications, Digital and Brand teams at CLIC Sargent and Teenage Cancer Trust for their time and expertise.

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<sup>1</sup> Based on an 2405 average annual cases of cancer in young people aged 15-24 diagnosed in the UK between 2012-14. Cancer Research UK. Teenagers' and Young Adults' Cancers Incidence Statistics. [Internet]. 2016. [cited 28 July 2017] Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/teenagers-and-young-adults-cancers/incidence>



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## FOREWORD

Thankfully, children, teenagers and young adults rarely get cancer, but each year in the UK 4,000 will get that diagnosis. As it's rare, it is often difficult to identify, diagnosis may come late and treatment be difficult. Children, young people and families had been telling me about the difficulties they had as well as the support they received. I set up the All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer (APPG CTYAC) to give Parliamentary attention to this specific group of people and their needs. I am very proud to be working with CLIC Sargent and Teenage Cancer Trust, who provide the Secretariat to the APPG so ably.

When we launched, young people told us that they wanted us to look at their experiences of being young people with cancer. We have made this our first Parliamentary Inquiry because we want their voices to be heard in Parliament, and because we believe that there are some solutions to some of their problems which we can achieve if we work cross-party and listen to what children, young people and families are saying about their experiences with cancer treatment.

I want to say a big thank you to Priyanka Patel and Ben Sundell for your hard work writing the report, to other staff at CLIC Sargent and Teenage Cancer Trust for organisation and support. Thank you to the panellists and those professionals and policy makers who gave written or oral evidence and to the ministers who were so open to being asked questions about current and potential provision for children and young people.

But the biggest thank you goes to the young people and parents of children with cancer who helped in so many ways – framing the purpose of the Inquiry, taking part in the survey, being involved in the Facebook Live consultation session and particularly to Katie Young and Tim Sadler for being panellists at the oral evidence sessions. Your generosity in helping us to learn from your experience, for the benefit of other children, young people and their families, is inspiring.

*Thangam Debbonaire*

**Thangam Debbonaire**  
MP, Chair, APPG CTYAC

# EXECUTIVE SUMMARY

This report concludes the first Parliamentary Inquiry by the All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer (APPG CTYAC), into patient experience for children and young people with cancer. It reviews research and other evidence on patient experience for children and young people with cancer, assesses how their needs are being met by cancer services and other statutory bodies across the UK, and makes recommendations for change. With this report, the Group hopes to help decision-makers across the UK understand what matters most to children and young people with cancer and support them to deliver it.

The APPG CTYAC is recommending action in the following areas:

## DIAGNOSIS

The APPG heard from a range of young people and parents about their experiences of diagnosis. Our survey of young people found that almost three-quarters of young people responding (73%, n=108) did not think enough was being done to improve experiences of early diagnosis.

The APPG heard evidence from health professionals on the difficulties with diagnosing cancer in children and young people. Witnesses highlighted the importance of training healthcare professionals on the signs and symptoms of cancer in children and young people, as well as educating and empowering young people and parents to take control of their own health.

The APPG therefore recommends the following:

- **RECOMMENDATION 1:** The Secretary of State for Education should ensure that every young person receives education and awareness of cancer signs and symptoms, as a compulsory part of the curriculum in secondary schools.
- **RECOMMENDATION 2:** Governments across the nations of the UK should provide appropriate, tailored information and/or training for healthcare professionals (with a focus on GPs) on the signs and symptoms of cancer in children and young people, to help them identify when to refer to specialists.

- **RECOMMENDATION 3:** NHS England's Children and Young Adult Cancer Services Clinical Reference Group (CYA CRG) service review should ensure clear responsibility for specialist Children, Teenage and Young Adult (CTYA) services to build relationships with primary care and enable a smooth patient experience from the point of diagnosis.

## DURING TREATMENT

The APPG heard that specialist, age-appropriate treatment and care for children and young people with cancer is usually vital and often helped with patient experience. However, the specific ways which children and young people with cancer in the UK receive treatment presents challenges. The financial impact of cancer and the practical impact of travelling long distances for treatment were raised, as was the impact of treatment on education and employment, for patient and parents. The APPG notes that addressing these challenges involves several government departments responsible for support for children, young people and their families during and beyond treatment.

- **RECOMMENDATION 4:** The Department of Work and Pensions should review benefits available to young cancer patients and their families. Young people and parents should have Disability Living Allowance or Personal Independence Payments they are entitled to, backdated to the date of diagnosis or made available from diagnosis.
- **RECOMMENDATION 5:** Governments across the UK should commit to reviewing the travel assistance available to young cancer patients and their parents/carers and make recommendations for reform.
- **RECOMMENDATION 6:** The Department of Health and Social Care should ensure full implementation of its 2014 'NHS patient, visitor and staff car parking principles' guidance on hospital car parking in England, and make sure Trusts are clearly promoting

concessions schemes for children and young people and their families when they are going to treatment.

- **RECOMMENDATION 7:** The APPG CTYAC calls on the Department of Health and Social Care to ensure NHS Trusts provide designated parking spaces for families of children and young people undergoing treatment or make other arrangements to help parents to park when bringing children for cancer treatment.

## POST-TREATMENT SUPPORT

The Inquiry's survey found that 73% (n=108) of parents and young people didn't think enough was being done to ensure access to post-treatment support. Witnesses identified several ways in which children and young people's post-treatment support needs were not consistently being met. This includes mental health support, access to education and access to fertility treatment in the long-term. The APPG notes again that this involves different government departments, as well as NHS England, considering changes to policy and practice to ensure children and young people are supported to reach their full potential following treatment.

- **RECOMMENDATION 8:** The Department of Health and Social Care should ensure that the mental health support that a child, young person or parent needs is a key part of their diagnosis, treatment, follow-up plan and recovery package.
- **RECOMMENDATION 9:** NHS England should engage with children and young people with cancer and their families to ensure the recovery package meets their specific needs
- **RECOMMENDATION 10:** The Department of Health and Social Care and Department for Education should re-examine their proposals in the Mental Health Green Paper and take account of the effect of a long-term physical health condition on young people's mental health.



- **RECOMMENDATION 11:** The Department for Education should ensure that all rescheduled public (GCSE, A Level and apprenticeship) exams are free to young people who missed the scheduled exam due to treatment or impact of illness.
- **RECOMMENDATION 12:** Children and young people with cancer and their parents or carers should have the risks of treatment discussed with them and be advised about their options for fertility preservation in an age-appropriate way before cancer treatment starts, in accordance with NICE guidance.
- **RECOMMENDATION 13:** Survivors of childhood cancer who were not offered fertility preservation before receiving cancer treatment should be able to access free fertility treatment.

### GETTING CHILDREN AND YOUNG PEOPLE'S VOICES HEARD

The Inquiry survey found that 64% (n=94) of the respondents did not think enough was being done to create a positive experience for children, teenagers and young adults with cancer. The lack of patient experience data for under-16s was flagged by witnesses as a

challenge for understanding whether the needs of this group are being met by cancer services. Work is currently being undertaken to scope how data can be captured from children and to identify what information is useful to collect, the APPG welcomes this and urges all governments across the UK to act on the recommendations of the scoping exercise. 82% (n=120) of young people and parents responding to the survey did not think that the government listens to the experiences of young people with cancer and their families enough.

- **RECOMMENDATION 14:** Following the outputs and recommendations from NHS England's scoping exercise into collecting patient experience data from under-16s, all governments across the UK should commit to taking these recommendations forward and collecting patient experience data from children.
- **RECOMMENDATION 15:** All ministers from the Departments of Health and Social Care, Education, and Work and Pensions with responsibility for children across the UK should commit to meeting with a group of children and young people with experience of treatment for cancer, at least once a year.

# INTRODUCTION

## 1 | OVERVIEW



### 1.1 Extent and incidence of childhood cancer in the UK

Every year in the UK over 4,000 children and young people under 25 are diagnosed with cancer.<sup>2</sup> That means every day 11 children and young people hear the news they have cancer. 10 children and young people die from cancer every week in the UK.<sup>3</sup> Cancer is the biggest killer of young people by disease in the UK.<sup>4</sup>

### 1.2 Impact of treatment for childhood cancer

Cancer in children, teenagers and young adults is rare in the UK. But it is unique in the way it is treated and in the lifelong impact it can have on their lives. Children, teenagers and young adults with cancer and their families often have to travel

<sup>2</sup> Based on an 2405 average annual cases of cancer in young people aged 15-24 and an average 1800 annual cases in children aged 0-14 diagnosed in the UK between 2012-14. Cancer Research UK. Teenagers' And Young Adults' Cancers Incidence Statistics, Children's Cancers Incidence Statistics [Internet]. 2016 [cited 4 Oct. 2017]. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics>

<sup>3</sup> Based on average number of deaths per year, ages 0-14, 2012-14, Cancer Research UK. Teenagers' And Young Adults' Cancers Incidence Statistics, Children's Cancers Incidence Statistics [Internet]. 2016 [cited 4 Oct. 2017]. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics>

<sup>4</sup> Based on average number of deaths per year, ages 15-24, 2012-14, Cancer Research UK. Teenagers' And Young Adults' Cancers Mortality Statistics [Internet]. 2015 [cited 4 Oct. 2017]. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/teenagers-and-young-adults-cancers/mortality>

many miles to access the specialist treatment they need, treatment which can last up to three years. This can have a long-lasting impact on their life chances as they miss education and employment and have to learn to live with their new lives after cancer treatment.

### **1.3 The All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer**

The All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer (APPG CTYAC) was launched in October 2017, with the aim of being a strong, cohesive voice in Parliament for children, teenagers and young adults with cancer and their families. The Group aims to make sure that the issues that matter to children and young people with cancer, and their families, are reflected in cancer services across the UK.

### **1.4 Meeting the specific needs of children and young people with cancer**

Recent developments in cancer care across the UK have recognised that children, teenagers and young adults have a clear set of specific needs. However, the NHS is under increasing pressure, and while improvements have been made in cancer services across the UK, progress still needs to be made in key areas for children, teenagers and young adults. As health services adapt to new ways of working and funding, we have to make sure that children, teenagers and young adults with cancer are not forgotten.

### **1.5 The Inquiry**

The APPG's Inquiry seeks to understand the experiences of children and young people with cancer, and their families, and to identify whether their needs are being met by cancer services across the UK.

This inquiry gathered evidence using the following methods:

- a) An extensive literature review of existing research and insight into young cancer patients and their families' patient experience
- b) An online survey of young people with cancer, their families and health, social care and other professionals that work with children and young people with cancer
- c) A Facebook Live Q&A session, allowing young people, parents and health professionals to share feedback and observations about cancer patient experience with members of the Inquiry panel
- d) A series of scrutiny sessions in Parliament with oral evidence from the government, NHS stakeholders, charity sector representatives and representatives from the devolved nations. This was supplemented by written evidence from the Department for Work and Pensions and Department of Education.

### **1.6 This report**

This report concludes the APPG's Inquiry into patient experience. It brings together vital evidence on patient experience for children and young people with cancer and aims to identify whether their needs are being met by cancer services across the UK, making key recommendations for change. With this report, the Group hopes to help decision-makers across the UK understand what matters most to children and young people with cancer and support them to deliver it.

## 2 | CONTEXT



### 2.1 Specific ways that childhood cancer treatment affects families

To understand the experience of having cancer as a child or young person in the UK, it is useful to examine the specific ways that treatment affects families, which are different to the effects on adult cancer patients, as well as the policy context of how cancer services for children and young people are configured across the UK.

Cancer in children and young people is rare and the types of cancers that develop in children and young people are complex and differ from those that develop in adults.<sup>5</sup> In recognition of the specific needs of this group, cancer services across the UK have been designed with specific pathways that differ from those that adults receive. This will frequently mean that children and young people with cancer have to travel long

distances to access specialist services, and stay away from home, missing school and contact with siblings and wider family.<sup>6</sup> Parents or carers may have to take time off work to care for their child, take them to appointments and stay with them in hospital – affecting their employment and family income.<sup>7</sup>

### 2.2 Specialist cancer services for children and young people in the UK

In 2005, the NICE Improving Outcomes Guidance for Children and Young People with Cancer set out, for the first time, a recommended pathway for children and young people with cancer. This guidance was reviewed in 2014 and remained unchanged. It recommended that healthcare services for children and young people with cancer should be organised in the following way:

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<sup>5</sup> NICE (2014) Cancer services for children and young people. <https://www.nice.org.uk/guidance/qs55/chapter/Introduction>

<sup>6</sup> CLIC Sargent (2010) A long way from home

<sup>7</sup> CLIC Sargent (2016) Cancer Costs

- Care should be coordinated across the whole NHS and be as close to home as possible
- Multidisciplinary teams should provide cancer care
- All children and young people should have a clearly defined key worker
- Care should be appropriate for the child's or young person's age and type of cancer
- Time in the operating theatre and a children's anaesthetist should be available when needed
- Children and young people should be offered the chance to take part in research trials
- Cancer networks should make sure there are enough specialist staff.<sup>8</sup>

There are also specific guidelines for end of life care for children and young people with life-limiting conditions<sup>9</sup> that set out the care and support that children, young people and their parents can expect. We did not examine these as part of this Inquiry. They merit specific attention in the future work of the APPG CTYAC.

The ways in which children and young people in the UK access cancer services are different from those accessing adult services and can have practical implications which impact on cancer patient experience.

Cancer services for children and young people focus expertise in age-appropriate, specialist treatment centres across the UK and are supported by other services that are delivered closer to families' homes (shared care centres for children and designated centres for teenagers and young people). There is a network of 19 specialist hospitals known as Principal Treatment Centres (PTCs), for diagnosing and treating children's and teenage or young adult cancers across the UK.

In England, services are delivered across PTCs which are supported by shared care services and designated centres across the country, and regional Cancer Alliances.

In Scotland, services operate as one single, cohesive service, delivered across a Managed Service Network (MSN) for Children and Young People with Cancer. The service brings together doctors, nurses and therapists who work together in a coordinated way.

In South Wales, all services are delivered by the children's hospital in Cardiff and supported by shared care hospitals across the region. In North Wales all services are delivered by the children's hospital in Liverpool and supported by shared care hospitals across North Wales.

In Northern Ireland, services are delivered by one PTC supported by designated hospitals for young people.

Travelling to access specialist treatment presents a range of practical difficulties for children and young people and their families, identified in section 2.1.

## 2.3 Children and young people's cancer patient experience across the UK

A summary of each nation's approach and prioritisation of cancer patient experience for children and young people can be found below.

### 2.3.1 England

In July 2015, the Independent Cancer Taskforce published its report *Achieving World-Class Cancer Outcomes – A Strategy for England 2015-2020*, with the aim of radically improving the outcomes that the NHS delivers for people affected by cancer.<sup>10</sup> This was followed by an NHS England implementation plan, *Achieving World-Class Cancer Outcomes: Taking the strategy forward*.<sup>11</sup>

<sup>8</sup> NICE (2005) *Improving outcomes in children and young people with cancer*. <https://www.nice.org.uk/guidance/CSG7>

<sup>9</sup> NICE (2016) *End of life care for infants, children and young people with life-limiting conditions: planning and management*. <https://www.nice.org.uk/guidance/ng61>

The Strategy makes a number of recommendations for improving children and young people's cancer services. Significantly, the Strategy recognises the importance of a person's experience of their cancer care and states an ambition to put patient experience on an equal footing with other patient outcomes, and 'transform [the NHS] approach towards supporting people to live well outside hospital and to return to their lives as far as possible after treatment has ended.'<sup>12</sup>

The Strategy identified a need to consider the best structure for children and young adults (CYA) cancer services to ensure continued improvement on the care and experience that children and young people with cancer receive. Recommendation 43 of the Cancer Strategy set out that NHS England, working through the CYA Clinical Reference Group (CRG) should:

- Consider whether paediatric treatment centres should be reconfigured to provide a better integrated network of care for patients and families
- Establish clear criteria for designation and de-designation of treatment centres for teenage and young adult (TYA) patients
- Ensure that any transition gap between children's' and adult services is addressed
- Assess impact of proposals on travel times for families.

Notable within this recommendation is the emphasis within the Cancer Strategy that any review of services should be based on patient outcomes, including patient experience. NHS England's Children and Young Adult Cancer Service Clinical Reference Group (CYA CRG) have begun work on a national service review which "aims to deliver the recommendations set out within the Cancer Taskforce report and drive improvements in clinical outcomes and service experience for patients. The review will include a significant focus on the designation of, and relationship between, Primary Treatment Centres (PTCs) and Shared Care Teams."<sup>14</sup> The CYA CRG is expected to publish its recommendations in late 2018.

### 2.3.2 Wales

The Cancer Delivery Plan for Wales 2016-2020<sup>15</sup> was published by the Wales Cancer Network in November 2016 and sets out the Welsh Government's commitment to delivering the best possible cancer care and support for everyone affected by cancer.

The 2016 Cancer Delivery Plan placed an increased prioritisation on children, teenagers and young adults with cancer. This plan identifies that patient experience among children and young people is not as well understood as for other patients. Action 34 calls on the Wales national Cancer Implementation Group (CIG) to "deliver further patient experience surveys and develop a longer-term approach to embedding patient reported experience and outcome measure tools into service design, delivery and improvement."<sup>16</sup> The CIG aims to do this by:

<sup>10</sup> Independent Cancer Taskforce (2015) Achieving World-Class Cancer Outcomes: A Strategy For England 2015-2020. [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>11</sup> NHS England (2016) Achieving World-Class Cancer Outcomes: Taking the strategy forward. <https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf>

<sup>12</sup> Independent Cancer Taskforce (2015) Achieving World-Class Cancer Outcomes: A Strategy For England 2015-2020. [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>13</sup> Independent Cancer Taskforce (2015) Achieving World-Class Cancer Outcomes: A Strategy For England 2015-2020. [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>14</sup> NHS England, Children and Young Adult Cancer Services. <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b05/>

<sup>15</sup> Wales Cancer Network (2016) Cancer Delivery Plan for Wales 2016-2020. <https://gov.wales/docs/dhss/publications/161114cancerplanen.pdf>

<sup>16</sup> Wales Cancer Network (2016) Cancer Delivery Plan for Wales 2016-2020. <https://gov.wales/docs/dhss/publications/161114cancerplanen.pdf>

- Supporting Health Boards and Trusts to develop action plans based on the results of the Wales Cancer Patient Experience Survey (WCPEs)
- Reviewing the approach of the Wales Cancer Network and CIG to engaging and involving people affected by cancer in its work plans, and make recommendations for improvement
- Gather information on relevant local cancer patient experience work happening within Health Boards and Trusts to inform, share and support cancer services across Wales, and propose recommendations for involving people affected by cancer in service developments across Wales.<sup>17</sup>

### 2.3.3 Scotland

In March 2016, the Scottish Government released its cancer strategy *Beating Cancer: Ambition and Action*.<sup>18</sup> This outlines their ambitions for improving the prevention, detection, diagnosis and treatment and after care for people affected by cancer.

The Scottish Strategy makes little direct reference to children and young people but it identifies the Managed Service Network for Children and Young People with Cancer (MSN CYPC), a national network of healthcare specialists from different NHS boards across Scotland, as responsible for delivering the Scottish Government's vision set out in its strategy for cancer services for children and young people.

In 2016, the MSN CYPC published its report *Right Diagnosis, Right Treatment, Right Team, Right Place; The Cancer Plan for Children and Young People in Scotland 2016-2019*<sup>19</sup>, which sets out the vision for children and young people's cancer care. The main aim of the strategy is for all young patients with cancer to receive the right diagnosis

and the right treatment, by the right team in the right place during their treatment for cancer and afterwards. The strategy does not refer to patient experience, but states that "the MSN will work with others to develop patient reported outcome measures for children and young people with cancer", the findings of which will feed directly into the MSN's workplan, to improve outcomes and experiences.

### 2.3.4 Northern Ireland

Northern Ireland last published a cancer strategy ten years ago in 2008. The Regional Cancer Framework strategy aimed to set out a clear and comprehensive plan detailing how to reduce the burden of cancer in Northern Ireland across a number of areas, including improving the experience of people affected by cancer. However, progress against this aim for children and young people is unclear.

## 2.4 Children and young people's cancer patient experience – what do we already know?

**2.4.1** One of the key ways that patient experience data for cancer patients is captured is through the Cancer Patient Experience Survey (CPES), which is designed to assess how people are experiencing their cancer care and identify areas for improvement.

**2.4.2** Each year in England, 70,000 cancer patients aged 16 and over report to the CPES on a range of experiences related to their care. For example, how long they have had to wait before first seeing a hospital doctor or how clearly they felt the results of tests were explained to them.

**2.4.3** The results of the survey are used in the Cancer Dashboard, produced by NHS England and Public Health England, which is intended as a tool to help commissioners and providers to identify priority areas of improvement for services.

<sup>17</sup> Wales Cancer Network, Engagement, Experience and Involvement. <http://www.walescanet.wales.nhs.uk/engagement-experience-and-involvement>

<sup>18</sup> Scottish Government (2016) *Beating Cancer: Ambition and Action*. <http://www.gov.scot/Publications/2016/03/9784>

<sup>19</sup> Managed Service Network for Children and Young People with Cancer (2016) *Right diagnosis, right treatment, right team, right place; The cancer plan for children and young people in Scotland 2016 – 2019*. <https://www.youngcancer.scot.nhs.uk/admin/js/libs/tinymce/plugins/moxiemanager/data/files/cancer%20plan%20FINAL%2002.02.16.pdf>

**2.4.4** From analysis of CPES, we know that teenagers and young adults who are treated within specialist services in Principal Treatment Centres report more positive experiences in many areas of care than those that were not within PTCs.<sup>20</sup> However, the response rate for young cancer patients aged 16-24 has been falling steadily in recent years, from a high of 442 in 2010, to a low of 242 in 2017. Further to this, the survey has never collected data from under-16s before, which means we have very little information on children's experience of cancer care.

**2.4.5** Without meaningful patient experience data, it is difficult to develop indicators to drive improvements in children and young people's cancer patient experience. The Cancer Strategy in England made a recommendation committing NHS England to developing a methodology to collect patient experience data for under-16s for the first time. NHS England is making progress on this recommendation so that services are able to learn from children and young people's experiences as soon as possible.



<sup>20</sup> Furness et al (2017) Cancer Patient Experience in the Teenage Young Adult Population: Key issues and trends over time. An analysis of the national UK National Cancer Patient Experience Surveys 2010 – 2014



## 3 | THE INQUIRY

### 3.1 Scope of the Inquiry

**3.1.1** Following the launch of the APPG CTYAC in October 2017, the Group committed to focusing on patient experience. This has been identified by NHS England and in cancer strategies across the UK as being as important as clinical outcomes.

**3.1.2** A literature review of existing research and insight on patient experience for children, teenagers and young adults with cancer, and their families, was conducted by Teenage Cancer Trust and CLIC Sargent. This was used to inform the Inquiry.

**3.1.3** The aims of the Inquiry were:

- a) To understand the experiences of children and young people with cancer and their families
- b) To identify whether their needs are being met by cancer services across the UK.

**3.1.4** Having considered the literature review, the Inquiry established the following themes for investigation:

- a) Children and young people's experiences of diagnosis
- b) Experiences of treatment and how it affects their lives and those of their families
- c) Post-treatment support for children and young people
- d) How children and young people want their voices to be heard in the system.

### 3.2 Call for evidence

**3.2.1** The APPG launched its call for evidence in February 2018 and has gathered evidence for the Inquiry via the following methods:

- a) An extensive literature review of existing research and insight into young cancer patients and their families' patient experience undertaken by CLIC Sargent and Teenage Cancer Trust
- b) An online survey of young people with cancer, their families and health, social care and other professionals that work with children and young people

with cancer. This was distributed via Teenage Cancer Trust and CLIC Sargent's participation networks and social media and was open from the 26th February to 16th March 2018. This has allowed young people and parents to contribute their experience and insight. It also helped make sure that panellists in the Inquiry asked the questions that young people and parents want answered

c) A Facebook Live Q&A session, allowing young people, parents and health professionals to share feedback and observations about cancer patient experience with members of the Inquiry panel. This was a 30-minute session held on the 6th March from 1pm, live from the Houses of Parliament. Chair of the APPG CTYAC Thangam Debbonaire MP was joined by Diana Johnson MP and a young person who was treated on a Teenage Cancer Trust unit, Katie, as they discussed patient experience and responded to live comments from viewers.

d) A series of scrutiny sessions in Parliament with oral evidence from the government, NHS stakeholders, charity sector representatives and representatives from the devolved nations. This was supplemented by written evidence from the Department for Work and Pensions and Department of Education. These were held on the 25th April and 2nd May 2018 in Parliament.

### 3.3. Literature review

3.3.1 In order to best establish the terms of this Inquiry, in July 2017 Teenage Cancer Trust and CLIC Sargent conducted an extensive literature review of available evidence on young cancer patients and their families' patient experience. This review examines the areas typically associated with good patient experience, and those which require improvement. Some of the key themes identified include:

- The value of age-appropriate care – previous results from the Cancer Patient Experience Surveys (CPES) showed that teenagers and young adults treated within age-appropriate services reported more positive experiences of care than those who were not (including receiving appropriate information, communication from professionals and being supported by their peers)
- Teenagers and young people identified that access to other support services, such as psychology was important
- The importance to young people of effective communication about what was happening to them
- The importance of retaining contact and being able to reintegrate into school, work and friendships
- Post treatment is particularly challenging and young people need particular support here.

3.3.2 The review also highlighted that there are a number of gaps in our knowledge about patient experience for children and young people – of which the APPG Inquiry is keen to try and understand better:

- It is difficult to fully understand children's experience of services, particularly because of the lack of a children's cancer Patient Experience Survey for those under 16
- We lack information about CTYAC experiences of tertiary, shared or designated care
- There is not enough evidence about how parents view their child's experiences
- To what extent a Patient Record would be useful for young cancer patients and their families.

### **3.4 Online survey**

**3.4.1** The literature review into patient experience informed the development of a brief online survey aimed to gather focused feedback from young people, parents and healthcare professionals. The survey focused on three key areas: experiences of diagnosis, post-treatment support and getting children and young people's voices heard in the system. A full list of questions asked can be found in the Appendix.

**3.4.2** The survey was disseminated through the APPG mailing list, via social media and through CLIC Sargent and Teenage Cancer Trust's participation networks. The survey was promoted for three weeks in March 2018 and completed by 42 young people, 105 parents/carers and 30 professionals working with children and young people with cancer. The survey software CVENT was used to analyse the findings.

### **3.5 Facebook Live**

**3.5.1** On 6th March 2018, the APPG sought to gather additional evidence and feedback from young people and parents through a Facebook Live Q&A session.

**3.5.2** Young people and their families were invited to tune in to the live broadcast, share feedback on patient experience and submit questions via Facebook comments, while APPG members and a young person discussed their observations live.

**3.5.3** The broadcast lasted for approximately 30 minutes, and saw Katie, a young person who was treated on the Teenage Cancer Trust Hull unit in 2014, joined by APPG Chair, Thangam Debbonaire MP, and Diana Johnson MP, Katie's constituency MP.

**3.5.4** This session offered an opportunity for young people, their families and health professionals to get involved with the Inquiry by engaging with the panel directly. The session generated lots of discussion around key issues and has helped to inform our overall findings as well as prompt questions for the panel to ask witnesses at the scrutiny sessions.

### **3.6 Scrutiny sessions**

**3.6.1** The final evidence-gathering stage of the Inquiry saw the APPG hosting two 'scrutiny sessions' in Parliament. These gave the panellists (APPG officers and other interested MPs) the opportunity to hear oral evidence from relevant policy-makers and practitioners and question them on patient experience for children, teenagers and young adults with cancer. A full list of witnesses the scrutiny panel heard from can be found in the Appendix.

# FINDINGS

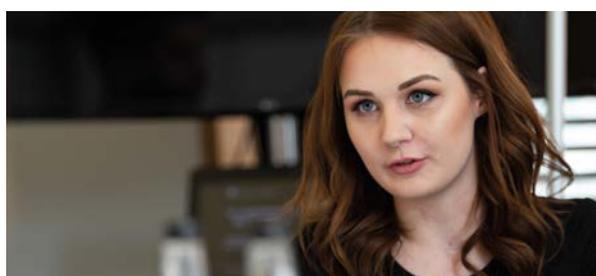
## 4 | DIAGNOSIS

**4.1** In the survey conducted for the Inquiry, 73% (n=108) of young people and parents who responded did not think enough was being done to improve experience of diagnosis.

**4.2** 56% (n=83) of respondents suggested that 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.

**4.3** In the APPG's Facebook Live session, Katie, who once diagnosed was treated on a Teenage Cancer Trust unit, spoke of her experience of diagnosis, outlining the difficulties she had to get to the point where doctors realised something was wrong.

*"I was going to the doctor's constantly for a year with various different symptoms. Looking back on my medical notes there were 50 notes on my record for one year – as a 19- or 20-year-old that's quite a lot. Then I broke down in tears to my GP saying that there was something wrong with me, I got told I had to*



*have telephone consultations and not come into the surgery any more because I was a nuisance patient. Shortly after that I ended up being rushed into A&E because I couldn't breathe and was in a lot of pain ... I had my bloods done and an X-ray and they just put it down to mental health issues and said that I was having a panic attack ... which I was adamant I hadn't. They told me the X-ray was completely clear and it was a really busy day in A&E. Six weeks later they told me they had double-checked it and they found a large mass growing in my chest ... and I was diagnosed with Hodgkin's lymphoma...*

*'I was quite lucky they found it by accident but so many patients on my ward had much worse experiences than me trying to get diagnosed...*

*It felt like if I was older and went with the symptoms I had I would be taken more seriously ... it felt like I was coming across as a melodramatic young person, but I didn't want to be spending all my time at doctor's."*

**4.4** Katie's experiences were reflected by participants who followed the Facebook Live session online. Comments included the following:

*"It took me 8 years of daily headaches to be diagnosed with a low-grade brain tumour. My family and I travelled to hospitals around the country to specialists and finally a private MRI we paid for in order to get a diagnosis! I totally agree that GPs and specialists need to be more informed to save lives of young people!"*

*"I'd like to know how we can make doctors take teenagers seriously. My daughter went for four years to a GP ... then in November found a tumour and unfortunately in December she passed away ... very upset that we have been let down."*

*"Doctors need to be made more aware of signs as early diagnosis is key to survival rates, my son was grade 4 by the time he was diagnosed and died 16 months later."*

**4.5** This was a view shared by practitioners we spoke to. For example, at the first evidence session, Dr Rachael Hough (Chair of the Children and Young Adults Clinical Reference Group) told the panel:

**"Definitely there is a big issue [with diagnosis] ... some patients, particularly teenagers, go to their GP multiple times, go to A&E multiple times, and often end up quite sick before they reach us."**

**4.6** When questioned by the scrutiny panel, the majority of witnesses agreed that delays to diagnosis are a particular issue for children and young people.

**4.7** Diagnosis of cancer in young people can be difficult due to the vague nature of symptoms, whereby symptoms being presented can often be misleading. Cancer in children and young people, compared to the prevalence rate of total cancers, is relatively rare and healthcare professionals

may see only a few cases in their entire career. Dr Rachel Hough told the inquiry that: "A GP might see one case in five years."

**4.8** Dr Clare Rowntree (National Clinical Lead for Teenagers and Young Adults with Cancer – Wales) identified the importance of education for young people about health, to help to change the systemic nature of the problem:

*"Once you hit sixteen there seems to be this abyss ... some of the cancers more common in the TYA age range, the brain tumours, the bone sarcomas, and lymphomas and you often hear very sad stories about very delayed diagnoses ... health professionals just don't often think that young people get cancer, but also, young people aren't empowered to use the system and once they get to 16 or 17 they perhaps lose the advocacy of their parents and they don't advocate for themselves very well..."*

*"Education of young people is where we could make a big difference ... the GPs training agenda is already rammed ... and somehow we have to change the model to put the empowerment with the young people..."*

*"Teaching young people how health services work and how to use them, and if you've gone back two or three times and you just don't feel you're being listened to, go somewhere else, go to A&E, and that has to be on the agenda."*

**4.9** Parliamentary Under Secretary of State for Public Health and Primary Care, Steve Brine MP also spoke about the importance of cancer education in schools to the panel. Referencing his visit to secondary schools in his constituency with Kris Hallenga, founder of Coppafeel, he said:

*"She spoke to them absolutely brilliantly about being breast aware and talking to your parents or your mothers about being breast aware, and about the boys being balls aware, and it was incredibly powerful. And that was probably about six years ago now, and people still remember Kris coming that day."*

**4.10** Thangam Debbonaire MP (Chair of the APPG) concluded this section by saying that:

*“GPs are used to expecting a woman in her 70s presenting chest pains that is quite possibly breast cancer, but we need to change the thinking [on young people because] although cancer happens rarely in young people, when it does it is really serious ... how do we get past the blockage of it being rare so it's difficult to treat?”*

**4.11** Challenges with early diagnosis were a recurrent theme in the Inquiry. Given the implications for poor prognosis of a late diagnosis, we would like clinicians, commissioners and policy makers to explore ways to improve education and awareness of how to spot signs and symptoms of cancer in young people.

**4.12** There are models to inform this work. Teenage Cancer Trust, for example, produce written resources and a short school-based presentation to inform young people about signs and symptoms of cancer. These resources are effective at helping young people understand the signs and symptoms of cancer themselves – 93% of students surveyed after they had witnessed a Teenage Cancer Trust presentation said it had increased their knowledge and understanding of the warning signs of cancer and 67% they felt more confident about visiting a doctor or nurse to talk about their health.<sup>21</sup> These resources could be adapted for healthcare professionals.

**4.13** Young people deserve to have the best possible information about signs and symptoms of cancer available to them. They should be equipped to be confident and able to take control of their own healthcare and future. Young people and parents of children with cancer have the right to expect that when they contact a healthcare professional, any warning signs of a serious condition, including cancer, will be picked up and they will be referred to the appropriate services for diagnosis.

**4.14** We also heard about the need for support for parents. For example, Dr Anthony McCarthy, (Consultant Paediatric Oncologist in Northern Ireland) said that:

*“You need to recognise just how frightened everyone is of that diagnosis ... parents need help to get them through this very difficult journey and ... find a way to normalise a very abnormal circumstance.”*

Prof. Hamish Wallace (National Clinical Director of the Managed Service Network for Children and Young People with Cancer, Scotland) agreed that:

*“We need to acknowledge that [parents] will have emotional needs.”*

**RECOMMENDATION 1:** The Secretary of State for Education should ensure that every young person receives education and awareness of cancer signs and symptoms, as a compulsory part of the curriculum in secondary schools.

**RECOMMENDATION 2:** Governments across the nations of the UK should provide appropriate, tailored information and/or training for healthcare professionals (with a focus on GPs) on the signs and symptoms of cancer in children and young people, to help them identify when to refer to specialists.

**RECOMMENDATION 3:** NHS England's Children and Young Adult Cancer Services Clinical Reference Group (CYA CRG) service review to ensure clear responsibility for specialist Children, Teenage and Young Adult (CTYA) services to build relationships with primary care and enable a smooth patient experience from the point of diagnosis.

<sup>21</sup> Opinion Leaders (2018) Impact and Outcomes Report for Teenage Cancer Trust

## 5 | DURING TREATMENT

### 5.1 Specialist care and support

In 2005, the NICE report 'Improving Outcomes Guidance for Children and Young People with Cancer' set out for the first time, an evidence base and recommended pathway for children and young people with cancer. A key tenet of this was examining feedback and research from young people about the experiences they had – helping to create a guideline about what good practice is from their perspective. It is clear that young people consistently report better patient experience outcomes where they get age-appropriate support. More recently, the establishment of the Children, Teenagers and Young Adults Clinical Reference Group means that advocacy of the needs of this group, and their families, has a structural embedding in the NHS. The group allows experts in this field to represent the specific needs of CTYA and directly feed them into service review and the development of future improvements. This group has so far produced service specifications for paediatric oncology and teenagers and young adults. Many of these services are provided in partnership by the NHS, CLIC Sargent and Teenage Cancer Trust, and are well evaluated, with findings demonstrating good service delivery.



**5.1.1** We received evidence via our online survey from young people and parents on the importance of being able to access specialist, age-appropriate treatment and care following diagnosis.

*"We cannot fault the NHS care we have received which was delivered in a specialist TYA centre and both my son and myself have been supported wonderfully."*

*Parent of a child with cancer*

*"I was diagnosed at my local general hospital where nobody really knew what to do with me – I had to choose between long distance travel or continuing to receive care that was blind to my specific emotional and social needs as a young adult. Nobody should have to make that choice."*

*Young person with cancer*

**5.1.2** The Inquiry heard oral evidence from CLIC Sargent Social Worker Louise Dolphin and Teenage Cancer Trust Lead Nurse Jamie Cargill on how their work helps to improve patient experience by supporting young cancer patients to navigate the health system following a cancer diagnosis.

**5.1.3** Jamie Cargill, Teenage Cancer Trust Lead Nurse, talked about his role in helping to advocate for young patients when they are undergoing treatment. Louise Dolphin, CLIC Sargent Social Worker, described her role as supporting children, young people and families with their non-medical needs – including everything from accessing financial grants and benefits during treatment, to support with accessing education.

**5.1.4** Dr Rachael Hough, Chair of the CYA Clinical Reference Group (CRG) told the Inquiry it was vital that healthcare teams considered the holistic needs of patients during treatment. She said the upcoming publication of the CRG's service specifications would ensure Principal Treatment Centres have clear responsibilities for making sure children, teenagers and young adults with cancer can access the holistic support they need.

## **5.2 Financial support**

We heard a lot about the financial impact of cancer on young people and families. 20% (n=29) of young people and parents responding to the APPG's call for evidence identified help with the financial impact of a cancer diagnosis as the biggest improvement that could be made to post-treatment support.

**“The costs from the moment of diagnosis are significant, whether that’s parking in a hospital – £44 a month – or having to eat out and stay away from home ... 50% of families give up work while their child undergoes treatment, they are faced with escalating costs and reduced incomes.”**

*Kate Lee, Chief Executive, CLIC Sargent*

**“It was fine for us because I had a good paying job and a car. But you see other families that don’t have that and it’s a struggle and worry. We got into debt, but we can afford to get into debt, but other people can’t – the added cost, is not something people take into consideration.”**

*Parent of a child with cancer*

**5.2.1** Dr Rachael Hough described the financial impact as being **“like a pebble in the water and the ripples go so far but aren’t always seen.”** She commented that the additional financial costs associated with cancer treatment in young people **“puts a huge strain on the family and I think it puts huge strain on the patient as well, because they know their illness is causing such difficulty in their family and they feel quite guilty.”**

**5.2.2** She highlighted concerns that currently, in her opinion, the benefits system is not adequately supporting young cancer patients, arguing that the lack of clear responsibility for meeting the additional needs of young cancer patients during treatment risks leaving them without the support they need:

**“Where does the NHS start and stop and where does the benefits and social care system start and stop? Some of these issues can fall through the gaps as there is an assumption that one or other of these systems is supporting patients.”**

*Dr Rachael Hough, Chair, CYA CRG*

**5.2.3** Existing financial support for children and young people with cancer, and their families, includes grants from charities and benefits such as Disability Living Allowance (DLA) and Personal Independence Payments (PIP). Respondents to

the APPG's survey highlighted several problems with the benefits system. These include the long wait for financial assistance, when the financial impact of cancer is often immediate:

*“Why do families have to wait for financial assistance, when diagnosis is immediate and children are already suffering with illness. It is a sudden effect on families to make decisions to stop working, pay for trips to hospital, stays in hospital, caring for their child. Extortionate car parking fees. Wear and tear on vehicles is not even considered. Public transport is often inaccessible, incorrect timing and an endurance that the child cannot possibly take. Family life stops, treats and outings go on the back burner.”*

#### **Parent of a child with cancer**

**5.2.4** The Inquiry received written evidence from the Minister of State for Disabled People, Health and Work, Sarah Newton MP, who said:

*“Young people, and indeed their families, who are living with a cancer diagnosis will be facing a traumatic time in their lives; the benefit system is there in order to support them in their time of need.”*

**5.2.5.** On the issue of the long waits to access benefits to help with the financial impact of cancer, the minister responded:

*“DLA and PIP provide a contribution towards the extra costs faced by severely disabled people as a result of long-term disability or health condition... Although some disabling conditions may appear to be long-term at their onset, this does not always prove to be the case. The earliest that entitlement to DLA/PIP can start is when a three-month qualifying period condition has been met. The three-month qualifying period helps establish that disability and the resulting care, supervision or mobility needs are of a long-standing nature, and ensures that the benefit goes only to those for whom it is intended.”*

**5.2.6** We would like the Department of Work and Pensions to look again at the qualifying period to receive benefits, with consideration of swifter decision-making and possible retrospective payments. This is to ensure children and young

people with cancer and their families have financial support at the time they need it most. In most cases, the day of diagnosis will mark the beginning of children and young people's 'time of need.

**RECOMMENDATION 4:** The Department of Work and Pensions should review benefits available to young cancer patients and their families. Young people and parents should have Disability Living Allowance or Personal Independence Payments they are entitled to backdated to the date of diagnosis or made available from diagnosis.

### **5.3 Travel costs**

The impact of travelling long distances to access specialist treatment was also flagged as an issue. The Inquiry heard from Kate Lee, who highlighted that the average family travels 440 miles a month for treatment, with 8% of families travelling over 1,000 miles a month.

**5.3.1** Dr Rachael Hough commented that the financial and practical impact of travel for treatment would be taken into consideration as part of the CYA CRG's service review, but that travel distances for are likely to be exacerbated in future. As new specialist therapies, such as Proton Beam Therapy and CAR T-cell therapy become available in the UK, these treatments will only be accessible in a handful of specialist centres, meaning that many families may have to travel further for treatment.

**RECOMMENDATION 5:** Governments across the UK should commit to reviewing the travel assistance available to young cancer patients and their parents/carers and make recommendations for reform.

### **5.4 Parking costs and availability**

Comments from parents in the APPG's survey and Facebook Live session drew attention to the significant cost of hospital car parking charges. CLIC Sargent Social Worker Louise Dolphin told the Inquiry that the local car park near Sheffield Children's Hospital charged families £14 a day,



with panellists reflecting on the difficulties faced by those on low incomes to meet these additional costs.

**5.4.1.** When questioned, the Parliamentary Under Secretary of State for Public Health and Primary Care, Steve Brine MP stressed that the Department of Health and Social Care has published tough guidance for NHS Trusts on hospital car parking. Hospitals should be offering free or reduced parking to young cancer patients and their families. However, the APPG heard evidence highlighting the inadequacy of this guidance in meeting the needs of young people and their families. Kate Lee told the Inquiry that **“guidance on parking can only work if it is promoted, and it is not promoted.”**

**RECOMMENDATION 6:** The Department of Health and Social Care should ensure full implementation of its 2014 NHS patient, visitor and staff car parking principles guidance on hospital car parking in England and make sure Trusts are clearly promoting concessions schemes for children and young people and their families when they are going to treatment.

**5.4.2** The Inquiry also heard about the challenges of finding a parking space in hospitals, which can add to the stress and anxiety of treatment. The panel reflected on the unique pressures that parents face – having to accompany children during hospital visits and being unable to drop off their child for treatment as they might if they were dropping off an adult patient. The need for designated accessible car parking spaces close to

hospital entrances for children and young people undergoing cancer treatment was viewed as a possible solution.

**RECOMMENDATION 7:** The APPG CTYAC calls on the Department of Health and Social Care to ensure NHS Trusts provide designated parking spaces for families of children and young people undergoing treatment or make other arrangements to help parents to park when bringing children for cancer treatment.

## 5.5 Access to treatment and clinical trials

While not a key area of focus for this Inquiry, the APPG did receive questions from parents and health care professionals on whether there is enough investment and research into treatments for children and young people’s cancers.

**5.5.1** The APPG recognises there are specific issues, especially for teenagers and young adults with cancer. Dr Rachael Hough explained that the national service review currently being undertaken by the CYA CRG will recommend the following changes to services to increase access for clinical trials:

- 1 Making sure children and young people are treated in designated treatment centres
- 2 Working with cancer networks who have responsibility for clinical trials
- 3 Trying to increase visibility to all patients and clinicians about what trials are available
- 4 Having a specific person for teenage cancer research within regional cancer networks
- 5 Improving the capacity for individual hospitals to host trials, by expediting the regulatory process required.

**5.5.2** We welcome this work and look forward to seeing the publication of the full service specifications for paediatric and TYA cancer services. This will be the subject of further investigation by the APPG in due course.



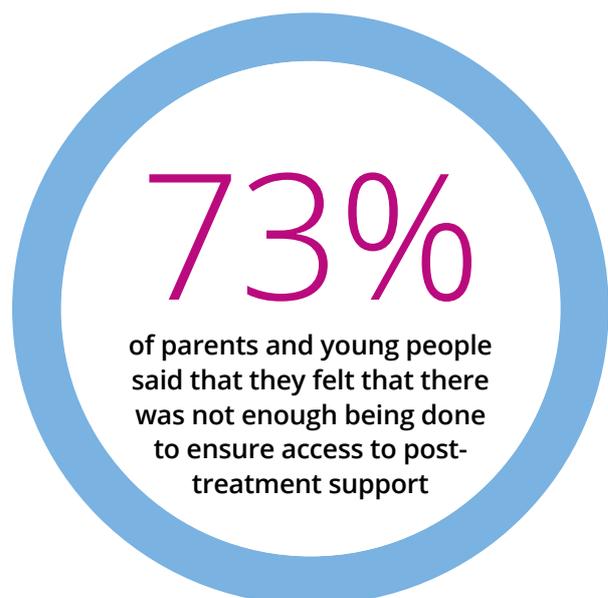
## 6 | POST-TREATMENT

### 6.1 Impact on children and young people's lives post-treatment

**6.1.1** Young people may experience a number of challenges in the post-treatment period as they transition to their new 'normal'. Cancer treatment can affect young people's physical and mental health, causing issues in fertility, disabilities, and having a negative impact on their mental health. We know it is important for children and young people to keep in touch with school and work, as well as friends and family, to support their sense of normality when going through treatment and improve their patient experience.

**6.1.2** In the survey conducted for this Inquiry, 73% (n=108) parents and young people said that they felt that there was not enough being done to ensure access to post-treatment support.

**6.1.3** Living well after cancer was identified as important by young people, parents and professionals. Some felt that access to appropriate emotional and mental health support was lacking.



**6.1.4** We note that fertility problems may come about many years after cancer treatment, and that not all patients will have had advice, information or medical interventions at the time of cancer treatment to help fertility later in life. We are aware that making blanket recommendations may not be possible, but we

would like the Department of Health and Social Care to review what is currently provided for young cancer patients and for adult survivors of childhood cancer to help them with fertility and to identify ways of improving this. Wherever possible we would like the impact of cancer treatment on fertility to be reduced and the potential for help with infertility to be increased.

**6.1.5** The survey revealed that 26% (n=38) of young people and parents identified help with mental and emotional help as the biggest improvement needed. The provision of more information about the long-term effects of cancer was also identified as important, with 21% (n=31) parents and young people stating this as the thing that would most improve post-treatment support.

**6.1.6** A parent wrote:

**“As a parent I do feel there is a distinct lack of post-cancer treatment support for teenage and young adult patients outside of TCT and CLIC.”**

**6.1.7** Those giving evidence to the Inquiry panel at the scrutiny sessions agreed that there were significant gaps in post-treatment support. Kate Collins, CEO Teenage Cancer Trust identified that:

**“Young people have told us that actually the experience of being spat out the end of treatment can be as traumatic as diagnosis, because all of a sudden you’ve been radically changed, you’ve been through this remarkable transformation experience in lots of ways, you’ve faced problems**

**that lots of adults have not had to face and you may also be fundamentally physically changed by your treatment, so you may be clear of cancer but often young people are living with long-term effects, be they psychological or physical.”**

**6.1.8** Nadhim Zahawi MP, Parliamentary Under-Secretary of State for Children and Families, submitted written evidence to the Inquiry as he was unable to attend the scrutiny session. In his submission he referred to the government’s plans for mental health provision, and how this might impact young people with cancer:

*“The Mental Health Green Paper<sup>22</sup> refers to a number of trailblazer areas ... these trailblazers may include alternative provision that pupils with cancer could attend while receiving treatment.”*

**6.1.9** However, it is important to highlight that the Green Paper on children and young people’s mental health makes no specific reference to the needs of young people with a long-term physical health condition. Whilst the APPG Children, Teenagers and Young Adults with Cancer’s Inquiry into patient experience has been running, a joint report from the Health and Education Select Committees<sup>23</sup> has been published which criticised the impact and reach of government proposals in the Green Paper:

**“The narrow scope does not take several vulnerable groups into account.”**

<sup>22</sup> Department of Health and Department of Education (2017) Transforming Children and Young People’s Mental Health Provision: a Green Paper. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/664855/Transforming\\_children\\_and\\_young\\_people\\_s\\_mental\\_health\\_provision.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/664855/Transforming_children_and_young_people_s_mental_health_provision.pdf)

<sup>23</sup> House of Commons Education and Health and Social Care Committees (2018) The Government’s Green Paper on mental health: failing a generation. <https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/642/642.pdf>

**6.1.10** It is clear from existing evidence compiled in the literature review, in line with the findings of this Inquiry, that those young people managing a cancer diagnosis are experiencing mental ill health at a significantly higher rate than the national average.

**6.1.11** Teenage Cancer Trust's report *What Really Matters to Young People with Cancer* (2016) 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.

**6.1.12** CLIC Sargent's *Hidden Costs* (2017) survey of young cancer patients showed 70% (n=98) had experienced depression, 90% experienced anxiety (n=128) and 42% (n=58) experienced panic attacks during treatment.

**6.1.13** The government's strategy to transform young people's mental health, 'Future in Mind', references the interface between mental and physical health, and suggests that "children with physical health problems also need their mental wellbeing and health supported."<sup>24</sup> There are however, no clear references to how this might happen in either the rest of this strategy or the subsequent Green Paper, published in 2017. The research outlines that 12% of young people will be living with a long-term condition.<sup>25</sup> It goes on to outline that the presence of such a chronic condition can significantly increase the risk of mental health problems.<sup>26</sup>

**6.1.14** When questioned directly by the scrutiny panel on the importance of post-treatment support, Parliamentary Under Secretary of State for Public Health and Primary Care Steve Brine MP recognised that:

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<sup>24</sup> Department of Health (2015) *Future in mind*. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414024/Childrens\\_Mental\\_Health.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf)

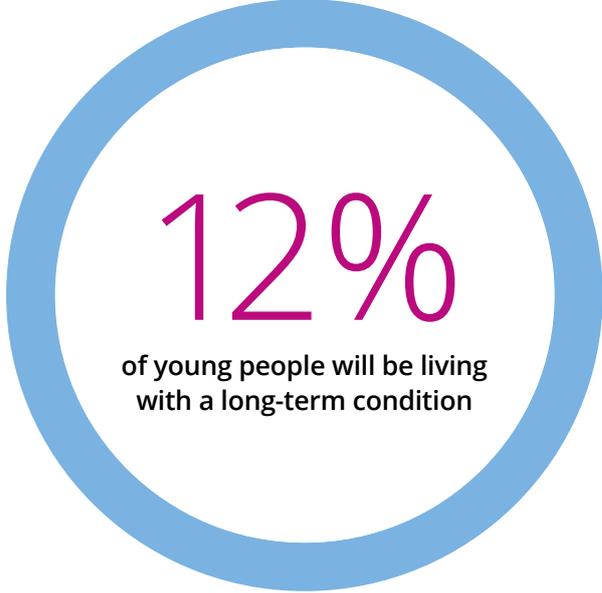
<sup>25</sup> (Sawyer et al 2007) in 'Future in Mind' (2015)

<sup>26</sup> (Parry-Langdon, 2008; Taylor, Heyman & Goodman 2003) in 'Future in Mind' (2015)



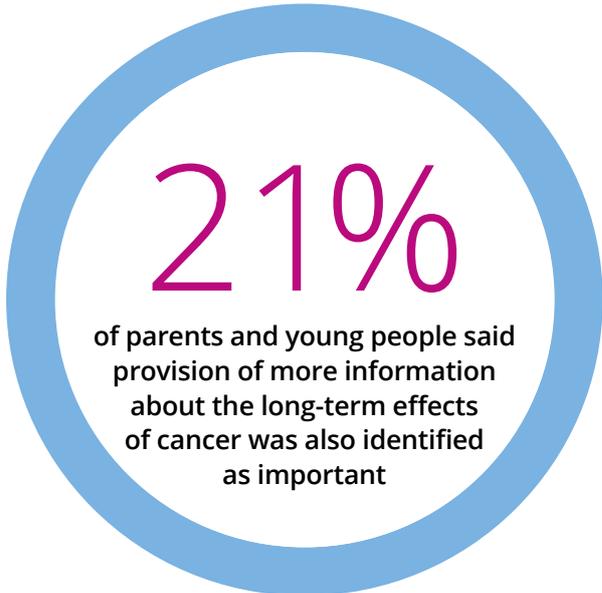
26%

of young people and parents identified help with mental and emotional help as the biggest improvement needed



12%

of young people will be living with a long-term condition



21%

of parents and young people said provision of more information about the long-term effects of cancer was also identified as important

**“For the 80% of children who survive, they’ve got it all ahead of them, so we have to make sure that we tool them up to live their lives.”**

**6.1.15** He said that his aim is that the Recovery Package, which is currently being rolled out across England, would be made available to all children and young people living with and beyond cancer by 2020.

**6.1.16** The Recovery Package is “a set of essential interventions designed to deliver a person – centred approach to care for people affected by cancer.”<sup>27</sup>

This includes:

- Holistic Needs Assessment (HNA) and care planning
- Treatment Summary (TS)
- Health and wellbeing events
- Cancer Care Review (CCR).

**6.1.17** Kate Lee, Chief Executive of CLIC Sargent however, told the panel:

**“The Recovery Package isn’t the solution to these problems as it doesn’t offer anything as comprehensive for CTYA’s as what CLIC Sargent and Teenage Cancer Trust provides.”**

**RECOMMENDATION 8:** The Department of Health and Social Care should ensure that the mental health support that a child, young person or parent needs is a key part of their diagnosis, treatment, follow-up plan and recovery package.

**RECOMMENDATION 9:** NHS England should engage with children and young people

with cancer and their families to ensure the recovery package meets their specific needs

**RECOMMENDATION 10** The Department of Health and Social Care and Department for Education should re-examine their proposals in the Mental Health Green Paper and take account of the effect of a long-term physical health condition on young people’s mental health.

## **6.2 Education and employment**

**6.2.1** Young people also wanted to know that they could get back on track with their education and employment. A young person wrote:

**“It was appalling that I was only given five hours of free education a week from my local government while I was unable to go to school. How is this able to ensure I keep up with my class? This provision was for children who couldn’t attend school for some reason and not solely for people unable to make it because they were ill, and so this is in no way sufficient to keep the children occupied or stimulated to learn. I ended up using this time for just maths lessons and then learning the rest of the curriculum with the help of family.”**

**6.2.2** Others highlighted more specifically the difficulties with maintaining links to education while they were undergoing treatment and issues with reintegration into education and employment after treatment. One young person wrote:

<sup>27</sup> NHS England (2016) Implementing The Cancer Taskforce Recommendations: Commissioning Person Centred Care For People Affected By Cancer. <https://www.england.nhs.uk/wp-content/uploads/2016/04/cancer-guid-v1.pdf>

“I underwent treatment for ALL (Acute Lymphoblastic leukaemia) which lasted two and a half years and I am now struggling to find something to do education/employment wise. I had to drop out of my first year of university when I was diagnosed and have been unable to return as my treatment has left me physically disabled. I feel like there is no help available to me to discuss options about work/education.”

**6.2.3** Louise Dolphin, CLIC Sargent Social Worker, told the panel:

“You have young people who are not only thrown out of the trajectory that they were on in terms of employment and education, but they don’t have the stability and the security and the resources to manage that and to cope with that, and I think that’s what makes this age range particularly unique.”

**6.2.4** She also explained that young people are often being charged for exams taken late, when treatment or illness prevent them from taking them at the scheduled time:

“If you miss your GCSEs or A Levels, very rarely are you able to take the full spectrum for free ... meaning that young people are not able to reach their full potential.”

**RECOMMENDATION 11:** The Department for Education should ensure that all rescheduled public (GCSE, A Level and apprenticeship) exams are free to young people who missed the scheduled exam due to treatment or impact of illness.

### 6.3 Fertility

**6.3.1** Having equal access to fertility preservation options was also cited as an important post-treatment consideration in the survey of young people. Quality Statement 7 under the Quality Standard for ‘Cancer services for children and young people’ recognises that “approximately 15% of patients have a high risk of future fertility problems because of their cancer treatment. Children and young people with cancer and their parents or carers should have the risks discussed with them and be advised about their options for fertility preservation before cancer treatment starts.”<sup>28</sup> However, there will be children and young people for whom fertility preservation is not an option. There will also be adults who may not have been offered this when they had cancer as a child.

**6.3.2** We recognise that fertility treatment and fertility preservation may not always be an option and that there will be limitations on these. We would like to see greater efforts made by the health service to ensure that adult survivors of childhood cancer are given the best possible chances of becoming a parent.

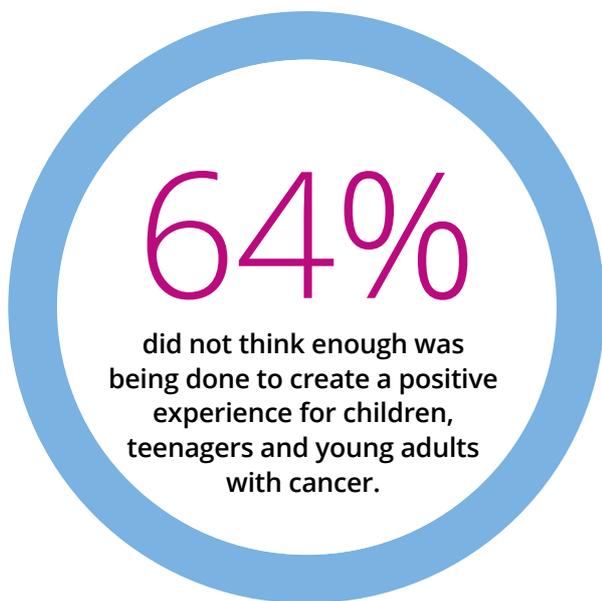
**RECOMMENDATION 12:** Children and young people with cancer and their parents or carers should have the risks of treatment discussed with them and be advised about their options for fertility preservation in an age-appropriate way before cancer treatment starts, in accordance with NICE guidance.

**RECOMMENDATION 13:** Survivors of childhood cancer who were not offered fertility preservation before receiving cancer treatment should be able to access free fertility treatment.

<sup>28</sup> NICE (2014) Cancer services for children and young people. <https://www.nice.org.uk/guidance/qs55/chapter/Introduction>



## 7 | **GETTING CHILDREN AND YOUNG PEOPLE'S VOICES HEARD**



The APPG's survey revealed that 64% (n=94) did not think enough was being done to create a positive patient experience for children, teenagers and young adults with cancer.

### **7.1 Cancer Patient Experience Survey (CPES)**

Steve Brine MP, the Parliamentary Under Secretary of State for Public Health and Primary Care, told the Inquiry that improving patient experience is one of the six strategic priorities in the Cancer Strategy for England. He also explained that one of the primary ways in which cancer patient experience is measured within the health system is through the Cancer Patient Experience Survey (CPES). The value and importance of CPES was echoed by other witnesses, including Professor Chris Harrison, National Clinical Director for Cancer, who argued that CPES is a vital indicator of what is happening in cancer care.

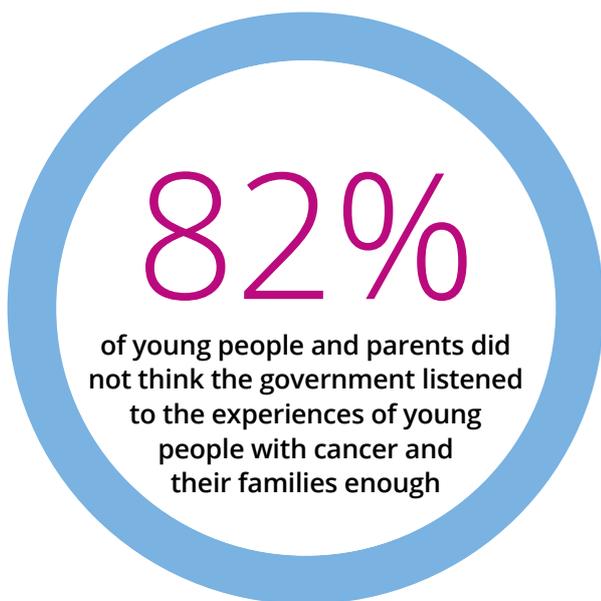
**7.1.1** The minister also pointed out that the most recent CPES data shows that cancer patients in England rated their care 9/10, which is a significant improvement from the 2015 survey.

**7.1.2** When questioned on how children's experiences of cancer care was captured, the minister told the Inquiry that NHS England will be looking at ways in which to extend the survey and capture under-16s patient experience data in 2018/19. Dr Rachael Hough also flagged the complexity of capturing patient experience data from children, and whether this should be directed at parents/carers as well as children themselves. NHS England has commissioned an external agency to undertake a scoping exercise looking into how under-16s want their experience to be captured, the specific information that needs to be collected and the involvement of parents and carers.

**7.1.3** Given the importance of CPES in highlighting strengths and areas for improvement in cancer patient care, the APPG welcomes the government's commitment to continue CPES. The APPG CTYAC also welcomes the progress being made into capturing patient experience data for under-16s in England.

## **7.2. Cancer patient experience across the UK**

The Inquiry heard from representatives from the devolved nations on how services currently engage with children and young people and how patient experience feedback is acted upon:



- Dr Clare Rowntree, National Clinical Lead for Teenagers and Young Adults with Cancer in Wales discussed how young cancer patients in Wales have an age-appropriate, designed service but that the services want to do more to capture patient feedback and improve young people's access to services
- Professor Hamish Wallace, National Clinical Director of the Managed Service Network for Children and Young People with Cancer, in Scotland, gave evidence to the Inquiry about how services for children and young people are designed in Scotland. He referred to the Managed Service Network (MSN), where there is an engaged youth forum who are able to impact service development for young people with cancer
- Dr Anthony McCarthy, Consultant Paediatric Oncologist in Northern Ireland, told the Inquiry about services in Northern Ireland, where patient experience data is collected by the charity sector and used to inform service developments.

**RECOMMENDATION 14:** Following the outputs and recommendations from NHS England's scoping exercise into collecting patient experience data from under-16s, all governments across the UK should commit to taking these recommendations forward and collecting patient experience data from children.

## **7.3 Listening to children and young people**

The APPG survey also found that 82% (n=120) of young people and parents did not think the government listened to the experiences of young people with cancer and their families enough.

**7.3.1** This sentiment was echoed by Kate Collins, Chief Executive of Teenage Cancer Trust, who argued:

**“This is fundamentally about young people getting heard, and young people do not believe that they are being heard, that they are being listened to, or that services that they need are being designed with them in mind, and that’s absolutely at the beating heart of what we have to have a laser-sharp focus on.”**

*Kate Collins, Chief Executive, Teenage Cancer Trust*



**7.3.2** When asked what young people felt could help ensure their voice is heard, 64% (n=94) felt that a minister with specific responsibility for cancer in children and young people could be a solution. In light of this, the Inquiry asked ministers from the Department of Health and Social Care, Work and Pensions and Education what existing engagement they had with children and young people with cancer and their families. They responded as follows:

- Steve Brine MP, the minister with responsibility for cancer told the Inquiry about his engagement with individuals affected by cancer as part of his ministerial brief and as a constituency MP. He also mentioned his regular stakeholder roundtable meeting with cancer charities
- Sarah Newton MP, the Minister for Disabled People, Health and Work described a range of ways in which the Department for Work and Pensions engages with external stakeholders, including through the Operational Stakeholder Forum and the PIP Forum. The Department also engages with the main cancer charities through external stakeholder forums and ad hoc meetings
- Nadhim Zahawi MP, the Parliamentary Under-Secretary of State for Children and Families told the Inquiry: **“The Department of Education does not directly engage with children affected by cancer or their parents. Children’s Cancer sits within the specialised commissioning in NHS England.”**

**7.3.3** We believe our Inquiry has found evidence of a clear need for different government departments to ensure they are listening to the experiences of children and young people with cancer and their families. For example, the Departments of Health and Social Care, Education and Work and Pensions and could commit to a regular meeting facilitated by the APPG CTYAC with children and young people affected by cancer and their families.

**RECOMMENDATION 15:** All ministers from the Departments of Health and Social Care, Education, and Work and Pensions with responsibility for children across the UK should commit to meeting with a group of children and young people with experience of treatment for cancer, at least once a year.

# CONCLUSIONS

## 8 | RECOMMENDATIONS

**8.1.1** While cancer in children, teenagers and young adults is rare, through this Inquiry, the APPG has heard how there are very few areas of life that are left untouched as a result of a cancer diagnosis.

**8.1.2** The unique way in which cancer is treated in children and young people in the UK means that young cancer patients have very specific needs that are not currently being addressed by the systems designed to be supporting them.

**8.1.3** The reality of being diagnosed with cancer as a child or young person means that there can be a significant impact on life chances. And the impact doesn't end once treatment stops.

**8.1.4** The APPG CTYAC will work with government and NHS leaders to ensure what matters to children and young people with cancer and their families is addressed and acted upon.

### **8.2 Recommendations**

Through analysis of written and oral evidence, the APPG CTYAC is making the following recommendations:

### **DIAGNOSIS**

**RECOMMENDATION 1:** The Secretary of State for Education should ensure that every young person receives education and awareness of cancer signs and symptoms, as a compulsory part of the curriculum in secondary schools.

**RECOMMENDATION 2:** Governments across the nations of the UK should provide appropriate, tailored information and/or training for healthcare professionals (with a focus on GPs) on the signs and symptoms of cancer in children and young people, to help them identify when to refer to specialists.

**RECOMMENDATION 3:** NHS England's Children and Young Adult Cancer Services Clinical Reference Group (CYA CRG) service review to ensure clear responsibility for specialist Children, Teenage and Young Adult (CTYA) services to build relationships with primary care and enable a smooth patient experience from the point of diagnosis.

## DURING TREATMENT

**RECOMMENDATION 4:** The Department of Work and Pensions should review benefits available to young cancer patients and their families. Young people and parents should have Disability Living Allowance or Personal Independence Payments they are entitled to backdated to the date of diagnosis or made available from diagnosis.

**RECOMMENDATION 5:** Governments across the UK should commit to reviewing the travel assistance available to young cancer patients and their parents/carers and make recommendations for reform.

**RECOMMENDATION 6:** The Department of Health and Social Care should ensure full implementation of its 2014 NHS patient, visitor and staff car parking principles guidance on hospital car parking in England and make sure Trusts are clearly promoting concessions schemes for children and young people and their families when they are going to treatment.

**RECOMMENDATION 7:** The APPG CTYAC calls on the Department of Health and Social Care to ensure NHS Trusts provide designated parking spaces for families of children and young people undergoing treatment or make other arrangements to help parents to park when bringing children for cancer treatment.

## POST-TREATMENT

**RECOMMENDATION 8:** The Department of Health and Social Care should ensure that the mental health support that a child, young person or parent needs is a key part of their diagnosis, treatment, follow-up plan and recovery package.

**RECOMMENDATION 9:** NHS England should engage with children and young people with cancer and their families to ensure the recovery package meets their specific needs.

**RECOMMENDATION 10:** The Department of Health and Social Care and Department for Education should re-examine their proposals in the Mental Health Green Paper and take account of the effect of a long-term physical health condition on young people's mental health.

**RECOMMENDATION 11:** The Department for Education should ensure that all rescheduled public (GCSE, A Level and apprenticeship) exams are free to young people who missed the scheduled exam due to treatment or impact of illness.

**RECOMMENDATION 12:** Children and young people with cancer and their parents or carers should have the risks of treatment discussed with them and be advised about their options for fertility preservation in an age-appropriate way before cancer treatment starts, in accordance with NICE guidance.

**RECOMMENDATION 13:** Survivors of childhood cancer who were not offered fertility preservation before receiving cancer treatment should be able to access free fertility treatment.

## GETTING CHILDREN AND YOUNG PEOPLE'S VOICES HEARD

**RECOMMENDATION 14:** Following the outputs and recommendations from NHS England's scoping exercise into collecting patient experience data from under-16s, all governments across the UK should commit to taking these recommendations forward and collecting patient experience data from children.

**RECOMMENDATION 15:** All ministers from the Departments of Health and Social Care, Education, and Work and Pensions with responsibility for children across the UK should commit to meeting with a group of children and young people with experience of treatment for cancer, at least once a year.

### 8.3 Areas for future inquiry

**8.3.1** The APPG recognises that not all children and young people will survive cancer. The issues and experiences of children and young people accessing palliative care and end of life treatment and support was not explored in great detail for the purposes of this Inquiry.

**8.3.2** Similarly, whilst parents were asked to contribute to the APPG's call for evidence, the specific needs of this group while their child undergoes treatment was beyond the scope of the Inquiry.

**8.3.3** The APPG CTYAC is grateful to all those young people, parents and health and care professionals who have contributed to the Inquiry. This report marks an important step in listening to young cancer patients and their families and making clear recommendations for change.



# 9 | APPENDIX

## Appendix 1 – What we asked

### Questions for everyone

- Do you think enough is being done to create a positive patient experience for children and young people with cancer and their families?
- Yes
- No
- Don't know

### Questions for professionals

- Tell us about yourself. I am a:
  - Doctor
  - Nurse
  - Consultant
  - Social worker
  - Youth worker
  - Psychologist
  - Work in an organisation that supports children and young people with cancer and their families
  - Other – please specify

- What top 3 things would improve patient experience for children and young people with cancer and their families?
  - More awareness of cancer in children and young people
  - Access to information and support to help with the impact of a cancer diagnosis on finances, education and employment
  - More opportunities to meet others going through a similar experience
  - Increased access to mental health/ emotional health support
  - Other – please specify
- What one question would you ask the Government about patient experience for children and young people with cancer?
  - Please include any additional comments you have below
  - If you would like to be kept updated on the work of the APPG CTYAC and receive a copy of the final report into patient experience please leave your email address below

## Questions for young people and parents

- **Tell us about yourself:**
  - I am a young person who has been diagnosed with cancer
  - I am between 13 and 16 years old
  - I am between 17 and 19 years old
  - I am between 20 and 25 years old
  - I am a parent of a child who has been diagnosed with cancer
- **Do you think there is enough being done to improve experiences of diagnosis?**
  - Yes
  - No
  - Don't know
- **What one thing would improve experiences of diagnosis?**
  - Training on cancer in children and young people for GPs
  - Education about cancer in schools for children and young people
  - Quicker access to tests
  - Quicker referral to specialists
  - Other – please specify
- **Do you think there is enough being done to ensure there is access to post-treatment support that is needed?**
  - Yes
  - No
  - Don't know
- **What one thing would improve post-treatment support?**
  - Support to help with the financial impact of a cancer diagnosis
  - Support to help with the impact of a cancer diagnosis on education or employment
  - More information about long-term effects
  - Opportunities to meet others going through a similar experience
  - Increased access to mental health/ emotional

- health support
- Other – please specify

- **Do you think that Government listens to the experiences of children and young people enough?**
  - Yes
  - No
  - Don't know
- **What one thing should the Government do to hear the voices of children and young people affected by cancer?**
  - For a Minister to have responsibility to meet children and young people with cancer and their families regularly to discuss their experiences
  - For the Government to increase ways young people and their parents can tell them about their experiences through online or social media platforms
  - Other – please specify
- **What one question would you ask the Government about patient experience for children and young people with cancer?**
  - Please include any additional comments you have below
  - If you would like to be kept updated on the work of the APPG CTYAC and receive a copy of the final report into patient experience please leave your email address below

## Appendix 2 – Who we heard from

The APPG heard from the following witnesses as part of the Inquiry:

### Session 1 – Wednesday 25th April 2018

#### Witnesses:

##### Steve Brine MP

(Parliamentary Under-Secretary of State for Public Health and Primary Care, brief including cancer, Ministerial Lead for NHS England and Public Health England)

##### Professor Chris Harrison

(National Clinical Director for Cancer, NHS England)

##### Dr Rachael Hough

(Chair of the Children and Young Adults Cancer Services Clinical Reference Group, Consultant Haematologist and Transplant Physician)

#### Panellists:

**Thangam Debbonaire MP** (Chair)

**Nic Dakin MP**

**Mark Tami MP**

**Karen Lee MP**

**Katie Young** (young person)

### Session 2 – Wednesday 2nd May 2018

#### Witnesses:

##### Kate Collins

(Chief Executive, Teenage Cancer Trust)

##### Jamie Cargill

(Teenage Cancer Trust Lead Nurse)

##### Kate Lee

(Chief Executive, CLIC Sargent)

##### Louise Dolphin

(CLIC Sargent Social Worker)

##### Dr Clare Rowntree

(National Clinical Lead for Teenagers and Young Adults with Cancer, Wales)

##### Prof. Hamish Wallace

(National Clinical Director of the Managed Service Network for Children and Young People with Cancer, Scotland)

##### Dr Anthony McCarthy

(Consultant Paediatric Oncologist in Northern Ireland)

#### Panellists:

**Thangam Debbonaire MP** (Chair)

**Nic Dakin MP**

**Mark Tami MP**

**Diana Johnson MP**

**Karen Lee MP**

**Dr Lisa Cameron MP**

**Tim Sadler** (parent)

The Group also received written evidence from **Sarah Newton MP**, the Minister for Disabled People, Health and Work and **Nadhim Zahawi MP**, Parliamentary Under Secretary of State at the Department for Education.





Teenage Cancer Trust is a registered charity: 1062559 (England & Wales), SC039757 (Scotland)  
CLIC Sargent is a registered charity in England & Wales (1107328) and Scotland (SC039857)

