



DEBATE PACK

Number CDP 2016/0232, 24 November 2016

E-petition debate on child cancer

This pack has been prepared ahead of the debate to be held in Westminster Hall on Monday 28 November 2016 at 4.30pm on an e-Petition,

[Force child cancer to the forefront of the NHS and government funding schemes](#)

The debate will be opened by Ben Howlett MP.

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

Dr Sarah Barber
Nikki Sutherland

Contents

1.	The E-petition	2
2.	Library note: E-petition on Child Cancer	4
2.1	Children's cancers	4
2.2	Cancer services for children	5
2.3	The Cancer Strategy	6
3.	News articles	9
4.	Press releases	10
5.	Parliamentary Material	25
5.1	PQs	25
5.2	Adjournment Debate	29
6.	Useful links and further reading	30

1. The E-petition

Force child cancer to the forefront of the NHS and government funding schemes

We want the government to make more funding available in the fight against child cancer. Not enough is being done to spread awareness. We need more genetic testing and research. Child cancer needs to be at the forefront of our minds. These beautiful children need our help, Please, lets help them.

My wife and I recently lost our precious daughter Poppy-Mai to a very rare cancer, it was a progressive and aggressive malignant rhabdoid tumour which progressed into a metastatic brain tumour. More funding should be made available in the fight against child cancer, these children are our future.

The [petition](#) has 115,748 signatures on 24 November 2016. It will remain open until 29 January 2017 and will be debated in Parliament in Westminster Hall on Monday 28 November 2016.

The Department of Health responded:

The independent Cancer Taskforce's five-year plan [Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020](#) (July 2015), includes recommendations on children and young people.

We want to lead the world in fighting cancer. Survival rates have never been higher, but we want to go further. The independent Cancer Taskforce's five-year strategy for cancer, *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020* (July 2015), recommends improvements across the cancer pathway with the aim of improving survival rates, awareness and the quality of care people receive.

Cancer services for children, teenagers and young adults (CTYA) have improved significantly and the NHS needs to consider the best structure for continued improved care and experience. The strategy has a number of recommendations with implications for CTYA as well as the following specific recommendations:

- 43: looks at a possible review of CTYA services to provide improved integrated care
- 44: consent from children and young people for their data and tissue collection for use in future research studies and development of services, and
- 45: that NHS England, National Institute for Health Research (NIHR) and cancer research charities to consider ways in which access to clinical trials for teenagers and young adults with cancer could be significantly increased.

An implementation plan *Achieving World-Class Cancer Outcomes: Taking the strategy forward*, was published May 2016 and the Board published its first annual progress report in October 2016.

NHS England already has the funds necessary to improve cancer services over the next five years as part of commitments in the Mandate and the additional £10 billion of funding. The recommendations in the independent Cancer Taskforce's report give direction as to where these funds should be targeted to achieve world-class cancer outcomes.

Investment in cancer research by the NIHR has increased substantially from £101 million in 2010/11 to £142 million in 2015/16 including research relating to childhood cancers. A new Department of Health Task and Finish Working Group on Brain Tumour Research is bringing together clinicians, charities and officials to discuss how, working together with research funding partners, we can increase the level and impact of research into brain tumours, including those in children. The Working Group, chaired by Professor Chris Whitty, the Department's Chief Scientific Adviser first met October 2016 and the Government expects it will complete its tasks by September 2017.

- Through the establishment of the 100,000 Genomes Project, the UK continues to be world leader in using genomics to diagnose, treat and prevent rare disease and cancer.
- The project currently covers 193 rare disease categories including childhood cancers.
- Considerable investment has been made in the project to date including £350 million from DH via the National Institute for Health Research (NIHR) budget.
- The project is already providing answers and changing lives - the first children with a rare disease have received diagnoses through the project at Great Ormond Street Hospital.
- The UK Strategy for Rare Diseases, published in November 2013, sets out a strategic vision for improving the lives of all those affected by rare diseases. It contains 51 commitments to be implemented by 2020 and has been signed up to by the four countries of the UK.
- The UK has also been at the forefront of pan-EU action on rare diseases. The 2011 EU Cross-Border Healthcare Directive promotes European Reference Networks (ERNs) as centres of knowledge, skills and expertise.

We know that cancer can affect all areas of a person's life, including relationships, work, and finances – 83% of people say they are financially impacted by cancer. People require holistic support from diagnosis onwards, encompassing their physical, financial, psychosocial, and information and support needs, throughout their entire cancer journey.

As can be seen in the case of Poppy-Mai, a cancer diagnosis can have devastating consequences for the lives of young people and their families, and we are working hard to improve services for patients in England within the constraints of the resources available to the NHS. Care should be built around what matters to the young person and their family and carers so we are working closely with cancer charities to ensure patients get the support they need during and after their treatment.

The hospital travel costs scheme provides financial assistance to those patients who do not have a medical need for ambulance transport, but need assistance with travel costs. This is part of the well-established NHS Low Income Scheme, in which patients on low incomes or receiving specific qualifying benefits or allowances can be reimbursed in part or in full for travelling costs to receive treatment at hospitals including cancer treatment. It also can be claimed where the appointment has been made for a child.

Children and teenagers with serious or critical illnesses such as cancer are also entitled to apply for Disability Living Allowance or DLA (or a Personal Independence Payment if over 16).

2. Library note: E-petition on Child Cancer

An e-petition on the Parliament and Government petitions website calling for child cancer to be forced to the forefront of the NHS and Government funding schemes has received over 115,000 signatures. It will now be the subject of a Westminster Hall on 28 November 2016, Ben Howlett will lead the debate.

2.1 Children's cancers

Cancer in children is rare, accounting for 0.5% of all cancers in the UK, but it is the most common cause of death from illness in those aged 1-15 years.¹ The most common types of cancers to affect children are leukaemias and cancers of the brain and spinal cord. Cancer in children tends to affect different parts of the body to adult cancers, and responds differently to treatment.²

The success rates for treatment of children's cancers have improved significantly in last few decades. Cancer Research UK (CRUK) have recently announced that figures show that the rate of children dying from cancer has fallen by over 30% in the last 20 years. They report that much of this success is due to new chemotherapy regimens, and improved imaging and radiotherapy techniques.³

However, CRUK caution that despite this improvement, around five children still die of cancer in Great Britain each week, and those who do survive may live with long term side effects of treatment that can affect them in adult life. They report that more research is needed to look at new ways to treat children's cancers with fewer side effects.

Beyond the impact of the disease itself, the often long term treatment can also have significant effects on the child and the wider family. CRUK highlight evidence of increased withdrawal, anxiety and depression in childhood cancer survivors. They also outline the support available to the child and their family:

How cancer affects the child and their family

Although about 8 out of 10 children are now successfully treated, childhood cancer is still devastating for everyone concerned. Treatment can last for months, or even years, which means long stays in hospital and being away from the home, school, friends and siblings. School age children may fall behind. Even though children's wards have teachers to keep the children's school work up to date, side effects from the cancer and its treatment often make children very tired. They may feel like not doing anything at times, except having a cuddle with mum or dad.

Cancer Research UK scientists have found evidence of increased withdrawal, anxiety and depression in childhood cancer survivors

¹ CRUK, [Children's cancers](#), 2014

³ CRUK, [Children's cancer death rates drop over 20 years](#), 17 November 2016

9 months after diagnosis. They have been looking at how families cope when a child has cancer and what factors are important in making the child (and family) either more vulnerable or better able to cope with the cancer and its consequences.

As well as the doctors and nurses on the ward, you and your child will be supported by a number of professionals during and after treatment, including your GP, cancer nurse specialists, social workers, play specialists and a psychologist or psychotherapist.⁴

2.2 Cancer services for children

The National Institute for Health and Care Excellence (NICE) guidance on [Improving Outcomes in Children and Young People with Cancer](#) (CSG7, 2005) recognises cancer in childhood is rare and includes a wide range of cancers with small numbers of patients with each type of cancer. Hence, in order to improve treatment and survival of cancers, the national approach has been to commission these services for large populations of at least 2 million to maximise the opportunities for standardising care and evaluating outcomes. NHS England's service specification for paediatric oncology sets out that care is centralised in Principal Treatment Centres (PTCs) for Children's Cancer to ensure depth and breadth of cancer coverage.⁵ The PTC retains overall responsibility for the cancer treatment plan but defined aspects of care are delivered in a Paediatric Oncology Shared Care model provided through designated Units in a number of District General Hospitals (DGHs) outside these specialist centres. In most cases the PTC for children and teenagers & young adults is within the same trust and in all cases they should work closely together.⁶

NHS England's service model recognises that children with cancer are different to adults because they are children, and because the cancers common in childhood differ from those common in adults. Children's needs differ according to their developmental stage (emotional, social, psychological and physical) and the need to consider the impact on the wider family of a cancer diagnosis. NHS England's service specification notes that across the age spectrum, children are as different from each other as they are from adults. Therefore a holistic approach to needs assessment is an essential part of service design.⁷

NHS England, Teenage Cancer Trust and CLIC Sargent have developed a helpful introduction to services for teenagers and young adults with cancer. It explains the general standards of care to expect from the NHS:

- [NHS Cancer Services for Teenager and Young Adults](#) (November 2015)

Following on from the Coalition Government cancer strategy, [Improving Outcomes: A Strategy for Cancer](#), published in 2011, in January 2015

⁴ CRUK, [Children's cancers](#), 2014

⁵ From 2013 the children's cancer pathway has been commissioned through NHS England as a prescribed service. Clinical Commissioning Groups (CCGs) and Local Authorities may directly, or through other collaborative arrangements, commission other elements of the pathway.

⁶ NHS England Service Specification, [Paediatric Oncology](#) (2013)

⁷ *Ibid.*

NHS England announced a new independent cancer taskforce to develop a five-year action plan for cancer services to improve survival rates and save thousands of lives.⁸ The taskforce developed a new cross-system national cancer strategy to 2020, building on NHS England's vision for improving cancer outcomes as set out in the [NHS Five Year Forward View](#).⁹

A 2014 NICE Quality Standard on Cancer Services for children and young people provides a set of statements to drive improvement in care in this area.¹⁰ This includes that children and young people with cancer should be offered the opportunity to take part in clinical trials, that chemotherapy should be prescribed using an electronic prescribing system, and that children and young people with cancer, and their families should have a psychological and social needs assessment during their care.¹¹

2.3 The Cancer Strategy

The independent Cancer Taskforce's five-year strategy for cancer, *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020* was published in July 2015.¹² It included 93 recommendations for improvements across cancer treatment, support and research, with the aim of improving survival rates, awareness and the quality of care people receive. It included three recommendations specifically related to children and young adults with cancer, as well as a number of others with implications for children. The strategy set out the following headline ambitions:

- A decrease in the age standardised incidence of cancer and a reduction in the number of cases linked to deprivation.
- Reduction in the adult smoking rate from 18 per cent currently to 13 per cent by 2020.
- By 2020, 57 per cent of cancer patients should be surviving for 10 years or more.
- A reduction in variability by Clinical Commissioning group on one-year survival and a target of increasing one year survival to 75 per cent by 2020 (currently, 69 per cent).
- A move toward a more patient-centred service and continuing improvement in patient satisfaction data.
- The introduction of 'cancer dashboards' presenting headline data at CCG and provider level. This would include information on things such as: proportion of people receiving a firm

⁸ NHS press release, '[NHS launches new bid to beat cancer and save thousands of lives](#)', 11 January 2015

⁹ [PQ HL4935 \[on Cancer\], 25 February 2015](#)

¹⁰ NICE, [Quality Standard, Cancer services for children and young people](#), February 2014

¹¹ NICE, [Quality Standard, Cancer services for children and young people](#), February 2014

¹² Independent Cancer Taskforce, [Achieving world-class cancer outcomes. A strategy for England 2015-2020](#), July 2015.

diagnosis or cancer being excluded by certain time points;
cancer diagnosed via emergency presentations; proportion of
cancers diagnosed at an early stage.

The strategy then goes on to set out the actions and funding needed to meet these goals; it has a particular focus on prevention and early detection. It estimate that if the NHS fully implements the measures recommended, an additional 30,000 patients per year may survive cancer for ten years or more by 2020 of which almost 11,000 will be through earlier diagnosis.

The strategy included the following section on children, teenagers and young adults (CTYA), noting improvements in services:

Cancer services for children, teenagers and young adults (CTYA) have improved significantly and deliver better outcomes for patients. In children (aged 0 – 14) in particular, five-year survival has increased from 40% in the early 1970s to 82% today¹³. However, some types of children’s cancer remain very hard to treat. Furthermore, many patients suffer long-term physical and psychological consequences of their treatment in to adulthood. Over the last few decades, the impact of some of these longer-term consequences has reduced, as we have better understood them and reduced the intensity of treatments given.

The NHS needs to consider the best structure for CTYA cancer services to ensure we continue to improve on the care and experience that patients receive. Outside London, only four centres treat more than 100 children with cancer per year, across all types of cancer. There is an opportunity to consider whether outcomes could be improved through further reconfiguration of services. Any review should be based on patient outcomes, including patient experience, as few centres offer comprehensive specialist services for children. Transitions continue to pose a problem in some areas, with paediatric services stopping at 16 in some hospitals but adult services not starting until 18. In addition, pathways between specialist centres and shared care units currently cause a great deal of difficulty for patients. This needs to be addressed.

The strategy made three specific recommendations relating to CTYA services:

- 43: looks at a possible review of CTYA services to provide improved integrated care
- 44: consent from children and young people for their data and tissue collection for use in future research studies and development of services, and
- 45: that NHS England, National Institute for Health Research (NIHR) and cancer research charities to consider ways in which access to clinical trials for teenagers and young adults with cancer could be significantly increased.¹³

A Department of Health [news story](#) published on 13 September 2015 gave details on how some of the measures in the strategy would be taken forward. This includes a pledge that by 2020, people with

¹³ Independent Cancer Taskforce, [Achieving world-class cancer outcomes. A strategy for England 2015-2020](#), July 2015

suspected cancer will be diagnosed within 28 days of being referred by a GP.

3. News articles

Times

Children's cancer deaths down a third in 20 years

Chris Smyth 18 November 2016

<http://www.thetimes.co.uk/article/children-s-cancer-deaths-down-a-third-in-20-years-2r07zg0n2> [subscription required]

Guardian

Scientists find 'chink in armour' of aggressive childhood cancer

Researchers believe they have found way to treat malignant rhabdoid tumours, which can kill children within months of diagnosis

Sarah Boseley 25 October 2016

<https://www.theguardian.com/science/2016/oct/25/scientists-find-chink-in-armour-of-aggressive-childhood-cancer>

Independent

Leading charity refutes claim cancer in young people rose 40 per cent

No evidence cancer in children caused by 'modern life', says Cancer Research UK

Harriet Agerholm 5 September 2016

<http://www.independent.co.uk/news/uk/home-news/leading-charity-refutes-claim-cancer-in-young-people-rose-40-per-cent-a7225211.html>

Telegraph

Modern life is killing our children: Cancer rate in young people up 40 per cent in 16 years

Sarah Knapton 3 September 2016

<http://www.telegraph.co.uk/science/2016/09/03/modern-life-is-killing-our-children-cancer-rate-in-young-people/>

BBC News Online

Child cancer concerns 'ignored by GPs'

11 February 2016

<http://www.bbc.co.uk/news/health-35536218>

4. Press releases

Together for Short Lives

Palliative care charities on the brink of state funding crisis

21 November 2016

- Cuts and freezes in statutory funding for children's hospice and palliative care charities means a bleak outlook for seriously ill children and families in England.
- Local authority funding for children's palliative care charities has fallen dramatically, down by 61% over the last year - only contributing 1% of the money needed.
- Statutory funding of adult hospices is frozen and distribution varies widely.

Statutory funding for children's hospices and palliative care charities in England is falling, according to findings released today by national charities, Together for Short Lives and Hospice UK. Local authority funding has been cut dramatically, with an average reduction of 61% as reported by children's palliative care charities. And the picture for adult palliative care is also worrying: nearly two thirds of hospices for adults (65 per cent) have had their statutory funding frozen or cut in the last financial year (46 per cent frozen, 19 per cent cut).

Services for seriously ill children under threat

Children's palliative care charity funding is facing a crisis. There are 40,000 children and young people with life-shortening conditions in England and the number is growing. The cost of caring for an increased number of children with complex health conditions is rising, but government funding is failing to keep pace – in fact, it's declining.

The survey of statutory funding for children's hospice and palliative care charities in England (looking at local authority, Clinical Commissioning Groups and NHS England funding) reveals a desperately bleak outlook:

- Cuts mean that local authorities are now only contributing 1% of the money charities need to provide palliative care to seriously ill children. This is despite the duty that councils have to provide short breaks (respite) to all disabled children and young people.
- On average, the overall amount of statutory funding for charities providing children's palliative care continues on a downward trajectory, falling year on year (22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14).
- Rising care costs are not matched by statutory funding. The cost of delivering lifeline care and support to seriously ill children in 2015/16 was nearly 10% greater than it was in 2014/15.
- There is heavy reliance on the Children's Hospice Grant: Nearly 60% of children's hospice services say they would be forced to

reduce their services if the NHS England children's hospice grant was no longer available. And over two thirds would be most likely to cut short breaks - leaving families, without respite care, at breaking point. NHS England is consulting on this grant and evidence from this report suggests it needs to be greatly increased.

- Charities delivering palliative care are worried that unless funding arrangements change they will not be able to meet the needs of these children and may have to cut existing services. This compounds the existing inequitable funding for children's palliative care across the country.

UK children's palliative care charity Together for Short Lives says it's not too late to prevent a crisis in children's hospice and palliative care funding.

Barbara Gelb OBE, CEO of Together for Short Lives, says:

"We urge the government to listen to children and their families and end this crisis in children's palliative care funding. The needs of this relatively small but nevertheless significant and growing number of children, with the weakest voice, are often not heard or ignored. Inadequate funding of children's palliative care services – across health and social care – means we are collectively failing the most vulnerable children in society, choosing to turn away from families who need help the most.

"We believe that ministers should follow the example of the Scottish Government, which has recently committed £30 million funding to Children's Hospice Association Scotland (CHAS) over the next five years. We're calling on the UK government to re-examine funding arrangements as a matter of urgency and carry out a national inquiry into the state of children's palliative care funding in England.

"We need to work together and act today to avert a painful crisis tomorrow. The Chancellor's Autumn Statement provides that opportunity. It's time to fund - not fail - services for seriously ill children and their families."

The picture for adults

Nearly two thirds of hospices for adults (65 per cent) have had their statutory funding frozen or cut in the last financial year (46 per cent frozen, 19 per cent cut). The lack of a coherent commissioning model nationally means the statutory funding of hospice care is effectively randomly distributed across England and is often not based on people's actual care needs at the end of life.

Tracey Bleakley, CEO of Hospice UK says the Government needed to pay attention to these early warning signs to avoid a commissioning crisis in adult palliative care:

"The current statutory funding situation for adult hospices is very concerning and poses a significant threat to the long-term sustainability of the sector.

"Hospices are having to deliver more year after year with standstill NHS resources, putting more pressure on community fundraising to help bridge the gap. This all comes when an ageing population is putting unprecedented demand on hospice care services

"There needs to be more investment and also fairer funding from the government for hospice care now - to supplement the vital support provided by local communities and prevent hospices reaching crisis point."

Read our report

Together with Hospice UK, we asked charities providing hospice and palliative care in England to tell us how much statutory money they receive. You can read our full findings and recommendations [here](#)

Cancer Research UK

Children's cancer death rates drop over 20 years

17 November 2016

The rate of children dying from cancer has fallen by more than 30 per cent in the last 20 years, according to the latest figures released by Cancer Research UK.

"Many children who survive cancer will live with long-term side effects of their treatment which may have an impact on them as adults, so it's vital that we find treatments that are not only better at treating the cancer but also have fewer side effects." - Professor Pam Kearns

The number* of children dying from cancer each year in Great Britain has fallen from around 340 two decades ago to around 240 today.

The figures show that cancer death rates** for all GB children under the age of 15 have fallen by 32 per cent, from around 31 deaths per million two decades ago to 21 deaths per million today thanks to more research and better treatments.

Much of this success is due to tackling childhood cancers by combining a number of different chemotherapy drugs. Cancer Research UK played a key role in the clinical trials that proved the benefits of these combined treatments, including [a large international trial \(link is external\)](#) that has helped lead to liver cancer death rates falling by 26 per cent in the last decade. Research to improve imaging and radiotherapy techniques is also playing its part.

But this still means around five children die from cancer each week in Great Britain so we still need research into new ways to tackle children's cancers. And improving treatment for children with cancer is a priority for Cancer Research UK. The charity funds research into many different

types of cancer that affect children. Researchers are working hard to understand the causes of children's cancer and the faulty genes that drive it, and they're leading clinical trials to test pioneering new therapies.

The new figures are announced as the Cancer Research UK Kids & Teens Star Awards, in partnership with TK Maxx, are launched. The Star Awards celebrate the courage of children and teenagers in the UK who have faced a cancer diagnosis, and everyone who is nominated receives an award.

Professor Pam Kearns is head of the Children's Cancer Trials team at the Cancer Research UK Clinical Trials Unit in Birmingham that is co-ordinating cancer trials for children and young people in specialist treatment centres across the UK to find the best ways to treat children and young people with cancer.

Professor Pam Kearns, Cancer Research UK's children's cancer expert, said: "Although we're losing fewer young lives to cancer, a lot more needs to be done to find better treatments.

"As more children survive cancer, it's especially important that we concentrate on improving the quality of life after treatment. Many children who survive cancer will live with long-term side effects of their treatment which may have an impact on them as adults, so it's vital that we find treatments that are not only better at treating the cancer but also have fewer side effects.

"Cancer Research UK's investment in clinical trials for children with cancer has been a major factor in developing today's treatments and is pivotal to ongoing research that will offer new hope to children and their families."

Cancer Research UK is also funding work searching for drugs to block faulty genes that cause a type of cancer that starts from nerve tissue called neuroblastoma. The charity is funding studies improving treatment options for children with a type of kidney cancer called Wilm's tumour and also work to understand more about how leukaemia develops and why it can return after treatment.

Professor Peter Johnson, Cancer Research UK's chief clinician, said: "We've made great progress in helping more children survive cancer year on year, but this work is not finished. Better, kinder treatments must continue to be our target. Our researchers are making great advances every year to help even more children beat the disease."

TK Maxx's support of Cancer Research UK's Kids & Teens Star Awards is part of a wider partnership with the charity, which has raised over £27.1 million through stock and cash donations. £23 million of this has specifically supported research into children's cancers, with a further £4 million supporting general cancer research, making TK Maxx the biggest corporate funder of children's cancer research in the UK.

To nominate someone for a Cancer Research UK Kids & Teens Star Award or to find out more about the campaign, visit [our website](#).

For media enquiries please contact the Cancer Research UK press office on +44 203 469 8300 or, out-of-hours, the duty press officer on +44 7050 264 059.

Notes to Editor

* Based on the average number of deaths from cancer for all cancers combined, including benign brain tumours for children (aged 0-14), in Great Britain, between 1994-1996 and 2013-2015

** Based on cancer mortality rates for all cancers combined, including benign brain tumours for children (aged 0-14), in Great Britain. Rates decreased from 32 deaths per million children between 1994-1996 to 21 deaths per million between 2013-2015

CLIC Sargent

Do not forget young cancer patients - CLIC Sargent comments on NHS England update on the Cancer Strategy

25 October 2016

Young cancer patients 'must not be forgotten' as NHS England works to improve cancer outcomes, CLIC Sargent warns. The charity welcomes the announcement of investment in radiotherapy care, but notes a lack of concrete progress for children and young people with cancer within an annual NHS report into improving cancer standards.

The [NHS England](#) update, released 25 October 2016, looks back on the steps taken toward achieving world class cancer outcomes in England following the recommendations of the 2015 NHS Cancer Strategy.

Although positive progress has been taken towards several outcomes, CLIC Sargent, the charity which supports children and young people with cancer, claims more needs to be done to address the specific challenges faced by young cancer patients.

[CLIC Sargent Chief Executive](#), Kate Lee, said: "While we welcome the positive work toward improving outcomes for adult cancer patients, young cancer patients, and the particular challenges they face, must not be forgotten.

"Young cancer patients often have a very difficult diagnosis and patient experience and as the NHS continues to work towards the challenging five year target it has set for itself, it is crucial that concrete steps are taken toward improving these experiences. This issue has also been raised in a recent report from the [All Party Parliamentary Group on Cancer \(opens in new window\)](#)."

While it is encouraging to see patient experience being treated with similar levels of importance as clinical targets, CLIC Sargent believes that quality patient experience data needs to be captured for children and young people.

At present no patient experience data is captured for under 16-year-olds with cancer. It is a recommendation for NHS England to deliver on in the next year and we look forward to working with them to make progress.

Children and young people with cancer, and their complex needs, must not be forgotten.

"Children and young people with cancer, and their complex needs, must not be forgotten. It is very important that their needs are understood, and more information will give greater clarity as to how the NHS, and later CLIC Sargent, can best support them."

The Independent National Cancer Advisory Group, of which Kate Lee is a member, has also highlighted that urgent action needs to be taken on workforce capacity in order to successfully deliver the recommendations of the Cancer Strategy.

Kate Lee added: "We will continue to work through the National Cancer Advisory Group and other avenues to make sure that every possible step is taken to improve the lives and experiences of children and young people diagnosed with cancer."

Editor's notes

For more information, an interview or images please contact Nick Edmondson on 020 8752 2856 or email nick.edmondson@clicsargent.org.uk. Outside office hours please call 08448 481189.

About cancer in children and young people

Every day, 10 children and young people in the UK hear the shocking news they have cancer. Treatment normally starts immediately, is often given many miles from home and can last for up to three years. Although survival rates are over 80%, cancer remains the single largest cause of death from disease in children and young people in the UK.

About CLIC Sargent

CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical and emotional support to help them cope with cancer and get the most out of life. For more information visit www.clicsargent.org.uk

Note to sub editors

Please note that the name 'CLIC Sargent' should not be abbreviated to CLIC, and that the word 'CLIC' should always appear in capitals, as above.

Department of Health

From 2020, people with suspected cancer will be diagnosed faster

13 September 2015

The government has pledged that from 2020, people with suspected cancer will be diagnosed within 28 days of being referred by a GP.

According to the Independent Cancer Taskforce, set up as part of the NHS's Five Year Forward View to examine how to improve cancer care and survival rates, the target to diagnosis all suspected cancer cases within 28 days could help save up to 11,000 lives a year.

Jeremy Hunt, the Secretary of State for Health said:

For people who are worried they may have cancer, waiting for that all important test result is a nerve-wracking time. We have a duty to make sure this period of uncertainty is as short as possible.

For those who get the all clear, they will have peace of mind sooner.

Those who sadly have cancer will get treatment much quicker and we will save thousands of lives as a result.

Mr Hunt also announced new measures to develop a tailored recovery package for everyone surviving cancer. A more personalised treatment plan and better support to live well, with and beyond the disease.

New measures to help personalise people's treatment and care include:

- around 20,000 additional people a year having their cancers genetically tested to identify the most effective treatments, reducing unnecessary chemotherapy sessions
- by 2020, patients will be able to access online information about their treatment and tests results
- access to physical activity programmes, psychological support and practical advice about returning to work
- help for those suffering with depression to make sure they have the right care at the right time
- by 2017, there will be a new national quality of life measure to help monitor how well people live after their treatment has ended, so priorities for improvements can be identified

The government has made a commitment that, by 2020, it will spend up to £300 million more on diagnostics every year to help meet the new 28 day target.

Health Education England will start a new national training programme that will provide 200 additional staff with the skills and expertise to carry out endoscopies by 2018. This is in addition to the extra 250 gastroenterologists the NHS has already committed to train by 2020. Endoscopies are tests where the inside of your body can be examined for cancer.

The newly trained staff will be able to carry out almost a half a million more endoscopy tests on the NHS by 2020.

Harpal Kumar, chair of the Independent Cancer Taskforce, said:

These commitments are going to save thousands of lives and deliver a step change in patient experience and quality of life, so this is fantastic news. Diagnosing more cancers earlier could transform patients' lives as it improves survival. But we've shown that services for diagnosing cancer are under immense pressure, which is why increased investment and extra staff are so important. Introducing the 28-day ambition for patients to receive a diagnosis will maximise the impact of this investment which, together with making results available online, will spare people unnecessary added anxiety and help cancer patients to begin treatment sooner.

It's also great that molecular diagnostic tests will be made routinely available to all patients who might benefit. These tests can help doctors provide more tailored treatments that may improve survival and potentially reduce side effects from less effective treatments.

At the heart of the recommendations in the cancer strategy is our desire for patients to have the best outcomes and care in the world. It's now up to the Government and NHS to make sure today's commitments are introduced without delay, and we await further detail on how they will take forward the rest of the strategy. This is a great start.

The NHS will identify 5 hospitals across the UK to pilot the new target before the programme is rolled out nationally by 2020.

CLIC Sargent

Cancer costs: financial impact of childhood cancer revealed

1 September 2016

Cancer in children and young people costs families an extra £600 a month on average, putting massive strain on budgets and causing many to fall into debt.

Research carried out by children and young people's cancer charity CLIC Sargent has revealed that costs can spiral when a child is diagnosed with cancer.

- Families spend extra £600 a month when child is treated for cancer
- Many plunge into debt as a result of extra costs
- Travel and food biggest additional spend

The charity has launched a new report [Cancer costs: The financial impact of treatment on young cancer patients and their families \(opens in new window\)](#) (1) and is campaigning for the Government, banks and energy suppliers to take action and help ease the financial burden when a child is diagnosed with cancer.

CLIC Sargent's research reveals three in five parents surveyed ended up in debt as a result of a child's cancer diagnosis – with one in six borrowing more than £5,000. The average extra spend of £600 per month is close to a third of the average UK monthly income, often putting a major strain on family budgets (2).

Treatment for children and young people's cancer can be miles from home at specialist treatment hospitals, requiring families to stay away from home for long periods of time, or embark on regular long distance travel.

These travel costs and additional food are the biggest extra expenditure but families also find themselves spending more on clothing, parking and accommodation while having to keep up with regular bills including mortgage, rent and energy.

The survey found cancer in children and young people also affected household income with 42% of parents stopping working after their child was diagnosed with cancer and 49% experiencing a loss of earnings. All this is on top of the worry and emotional impact that cancer diagnosis brings with three quarters of parents (76%) CLIC Sargent surveyed also reporting that managing their finances caused additional stress and anxiety.

In addition families reported that the benefit system was not fit for purpose for young cancer patients or their needs, often taking too long and still leaving families with a financial shortfall.

CLIC Sargent provides a £170 grant to families following diagnosis, to help with initial costs, and gave out £1.1 million in grants in 2015/16. It also provides free accommodation at 10 [Homes from Home](#) around the UK near hospitals where children are treated for cancer.

But the charity says more needs to be done and is calling on the government, banks and energy suppliers to provide more assistance to affected families.

It is calling for:

- A review of travel assistance available to parents and young people, with recommendations for reform to be made by the end of 2017
- Immediate financial support to be provided from the point of diagnosis to every patient
- Financial services and energy companies to review their vulnerable customers policies to ensure they include parents of children with cancer and young cancer patients.

Kate Lee, Chief Executive of CLIC Sargent, said: "The pressure of managing finances causes considerable stress and anxiety during what is an already impossible time for families. This is not right or fair.

"Following the initial shock of diagnosis, treatment often starts immediately and can take place far from home. Suddenly families see

their lives transform, as their priorities shift to support their child through their illness.

As our report reveals, hundreds of families are struggling to keep their heads above water financially and need more help.

"CLIC Sargent will continue be there for as many children and families as we can by providing [practical](#) and [financial support](#) but more needs to be done to ease this financial burden and help these families cope with the impact of cancer on their lives.

"That is why we are calling on the Government, banks, energy and transport companies to implement a series of measures that will make a real difference to families coping with childhood cancer."

CLIC Sargent has launched a petition to Prime Minister Theresa May to act now to ease the financial burden of childhood cancer. To sign the petition visit www.clicsargent.org.uk/ccam

September is [Childhood Cancer Awareness Month](#). [Lidl UK](#) has raised £1million for children and young people's cancer support charity CLIC Sargent and is the lead sponsor of Childhood Cancer Awareness Month.

Daniela Tulip, Head of CSR at Lidl UK, said: "CLIC Sargent's research has highlighted the very real issue of the cost of cancer for families across the UK.

"As headline sponsor of Childhood Cancer Awareness Month, Lidl UK is proud to support CLIC Sargent in its bid to ease this financial burden and make life that little bit easier for families struggling to cope with a childhood cancer diagnosis.

"Lidl recently achieved its target of raising £1 million for CLIC Sargent, six months ahead of schedule. This amount has enabled CLIC Sargent to fund 40,000 hours of care for children and young people, and their families, who are going through cancer treatment."

Editor's notes

(1) Survey carried out by 279 parents and 149 young people, recruited through CLIC Sargent networks, care professionals and social media.

(2) Based on ONS–LMSB SA AWE Total Pay WE. Released 17.8.16. Average weekly pre-tax income of £502. Series ID: KAB9

Cancer Costs Report

Two online surveys were carried out by 279 parents and 149 young people recruited through CLIC Sargent's networks, our care professionals and social media. All percentages reported are drawn from the number of people who answered each question, not the total sample size.

About cancer in children and young people

Every day, 10 children and young people in the UK hear the shocking news they have cancer. Treatment normally starts immediately, is often given many miles from home and can last for up to three years.

Although survival rates are over 80%, cancer remains the single largest cause of death from disease in children and young people in the UK.

Institute of Cancer Research

Children with cancer to get new gene test

31 March 2016

Pilot study will sequence 81 cancer genes in children's tumours to help personalise cancer treatment

Children with cancer at leading hospitals across the UK will be offered testing for genetic mutations in their tumours as part of a new initiative to begin to personalise children's cancer treatment.

Around 400 children with solid tumours at 21 hospitals across the country will start to receive the new genetic test, which is designed to pick up key mutations in tumours that drive cancer's growth and spread.

The initiative is the first stage of a wider programme which eventually aims to provide testing for all children with solid tumours in the UK, and to direct them into clinical trials targeting particular mutations within their tumours.

Researchers at The Institute of Cancer Research, London, and [The Royal Marsden NHS Foundation Trust](#) designed the new test, which works by sequencing 81 different cancer genes, with funding from UK charity [Christopher's Smile](#).

Testing will begin from 2016 and take about two years, with initial funding for the testing programme from the [NIHR Biomedical Research Centre](#) at The Royal Marsden and The Institute of Cancer Research (ICR).

Tests will first be offered to children treated at The Royal Marsden, and then to patients at any of the other 20 hospitals in the UK which form part of the [Children's Cancer and Leukaemia Group](#).

The initial aim will be to assess the reliability and usefulness of the test in a research setting. If testing is successful, the aim is to move testing more routinely into the clinic, to allow treating doctors to formally incorporate the results in their decisions about how patients can be most effectively treated.

The ambition is to offer children the same opportunities for personalised cancer treatment that are already increasingly becoming available for adults – to improve survival rates and reduce the level of side-effects.

The testing programme will establish which mutations occur most often in children's tumours, and identify those that could be targeted by existing drugs for adult cancers.

Doctors will aim where possible to use the test results to match children to clinical trials of targeted cancer drugs – although maximising this

potential will require more clinical trials of targeted treatments to be set up for children.

Targeted drugs can be highly effective at specifically attacking cancer cells while leaving healthy cells alone, and are likely to have fewer side-effects than standard cancer treatments.

But many of these drugs are not yet routinely available for children, in part because of difficulties in setting up clinical trials.

The new initiative will be open to children under the age of 14 with solid tumours. It will not initially include children diagnosed with blood cancers such as leukaemia unless they suffer a relapse, because these cancers respond very well to the current treatments. Nor will it include older teenagers or young adults as they experience a different spectrum of tumours to children.

Study leader [Professor Louis Chesler](#), Professor of [Paediatric Cancer Biology](#) at The Institute of Cancer Research, London, and Consultant at The Royal Marsden NHS Foundation Trust, said:

“Children deserve the very best, modern treatments for cancer, but for too long there have been delays in applying the latest molecular techniques to personalise their treatment.

“A more comprehensive and structured approach to genetic testing to match children with cancer to specific targeted treatments could be an incredibly important step towards increasing survival. It’s exciting to be testing out this new approach to genetic testing in several hundred children with cancer, in what I hope will be a staging post towards routine use of genomic information for the care of all children with cancer in the UK.

“We still face major barriers in obtaining targeted cancer drugs for children and using them in robustly designed clinical trials. But my hope is that through this and other initiatives like it, we can help to drive forward the use of targeted drugs in children, and make the case very clearly that they should be more widely available, as they have been for adults.”

Dr David Gonzalez de Castro, Head of Molecular Diagnostics of the [NIHR Centre for Molecular Pathology](#) at The Royal Marsden and the ICR, and developer of the genetic technology used in this study, said:

“We have been using genetic profiling in adult cancers for many years in the NHS, allowing successful treatment stratification based on the biology of the tumour. We now need to bring these advances to childhood cancers and be able to design novel trials and tailor treatments using genomic medicine.”

Karen Capel, founder and trustee of UK children’s cancer charity [Christopher’s Smile](#) who funded the development of the test, said:

“There is an urgent unmet need to provide new treatments for those children diagnosed with the most aggressive and hard to treat cancers. We believe this gene sequencing test is the key ‘foundation stone’ in

enabling personalised medicine for children. It will help to bring new treatments for children a step closer. We believe that children should be given access to the same tests and treatments currently available to adults.

“Christopher’s Smile has not only committed over £300,000 specifically for paediatric molecular pathology but we also campaign tirelessly at national and European levels to give children better access to the latest drugs.

“When our son died in 2008 there was no biological information available to clinicians about individual children’s tumours. This test is a first for children. Our aim is that it will change the landscape for children and open doors to potential new trials with new treatments, benefitting those children who receive the worst prognosis.”

NICE

Improving care for children and young people with cancer

27 February 2014

Children and young people with cancer should be given the opportunity to take part in clinical trials to increase knowledge about the disease and improve survival rates, according to latest standards from NICE.

Children and young people with cancer should be given the opportunity to take part in clinical trials to increase knowledge about the disease and improve survival rates, according to latest standards from NICE.

It is estimated that nearly 3,200 children and young people are diagnosed with cancer in England each year.

Cancers in children and young people differ from those that develop in adults, and are often more complex in nature. This can make them challenging to identify and to ensure that appropriate treatment is provided as quickly as possible.

However, the availability of more effective treatments has meant that survival rates have more than [doubled](#) since the 1960s. Now 78 per cent of children diagnosed with cancer survive for five years or more compared with just 28 per cent in the late 1960s.

A reason for this is the increasing number of children taking part in clinical trials for new cancer treatments, with recent [research](#) highlighting the link between survival rates and the number of clinical trials that have been carried out.

To help improve the care of children and young people with cancer, NICE has produced a [quality standard](#) which includes seven statements for providing high-quality care.

Among these statements is a call for children and young people aged up to 24 to be offered the opportunity to take part in clinical trials if they are eligible.

NICE acknowledges that the involvement of young people with cancer in clinical trials has made an important contribution to improved cancer survival rates. Consequently, it says multidisciplinary teams should identify suitable trials and key workers should provide support to the patient and their family in deciding whether to participate.

The quality standard also calls for children and young people receiving chemotherapy to have it prescribed using an electronic prescribing system.

NICE says that this will help address the number of risks associated with prescribing and administering chemotherapy, such as potential errors in calculating correct doses fluid volumes and scheduling. While electronic prescribing is widely used in adult cancer care, it is not available as extensively in all children's cancer services.

Due to the risk of long-term adverse effects from cancer and its treatment, the standard includes a statement on follow-up and monitoring of late effects.

NICE says children and young people (aged 0-24 years) who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

Additional statements cover psychological and social support for children with cancer, their families and carers, and support for potential future fertility problems.

Professor Gillian Leng, Deputy Chief Executive of NICE, said: "Clinical trials lie at the heart of drug development and without children and young people participating in research, there would be no new advancements in treatments and our knowledge of the disease would stall. Our new quality standard recognises this by recommending children and young people be given the opportunity to take part in relevant trials as long as they are eligible to take part and it is what they want to do."

John Anderson, Professor of Experimental Paediatric Oncology at Great Ormond Street Hospital, said: "These standards underline the importance of clinical trials.

"The progress in childhood cancer survival rates has been driven to a large extent by patient participation in national and international clinical trials. Participation of children and their parents in research has contributed to better treatments for those who partake, as well as improving future treatments."

Professor Alan Ashworth, Chief Executive of The Institute of Cancer Research, London, said: "Some childhood cancers remain incurable, and even among children who survive there are high rates of long-term side-effects. The only way to develop new and better treatments for children with cancer is to run more paediatric cancer trials.

"Treating children in clinical trials ensures consistent excellence in care, and means we can learn from every child's experience to improve treatment for others. We need to address the regulatory and financial

barriers that exist to running paediatric cancer trials, to ensure as many children as possible benefit from them."

5. Parliamentary Material

5.1 PQs

Cancer. Children

Asked by: Shannon, Jim

To ask the Minister for the Cabinet Office, how many children have been diagnosed with cancer in each of the last five years.

Answering member: Chris Skidmore | Department: Cabinet Office
| Asked to reply: UK Statistics Authority

The information requested falls within the responsibility of the UK Statistics Authority. I have asked the Authority to reply.

[http://qna.files.parliament.uk/qna-attachments/631176/original/PQ52079%20\(1\).pdf](http://qna.files.parliament.uk/qna-attachments/631176/original/PQ52079%20(1).pdf)

HC Deb 15 November 2016 | PQ 52079

Cancer. Research

Asked by: Debonnaire, Thangam

To ask the Secretary of State for Business, Energy and Industrial Strategy, what assessment he has made of the potential effect of the UK leaving the EU on research on rare and childhood cancers.

Answering member: Joseph Johnson | Department: Department for Business, Energy and Industrial Strategy

The Government is committed to maintain and enhance the strength of our research base. This is why we have protected the science resource budget in real terms from its 2015/16 level of £4.7 billion for the rest of the parliament, as well as committing to invest in new scientific infrastructure on a record scale – £6.9 billion over the period 2015-2021.

The Treasury decision to underwrite the grants of competitively bid for EU research funding will give British participants and their EU partners the assurance and certainty needed to plan ahead for collaborative projects that can run over many years. We are committed to ensure that the UK continues to be a world leader in international science, including medical research into cancer.

HC Deb 07 November 2016 | PQ 50081

Cancer. Children

Asked by: Shannon, Jim

To ask the Secretary of State for Health, what steps he is taking to improve early diagnosis of childhood cancers; and if he will make available additional funding to improve such early diagnosis.

Answering member: David Mowat | Department: Department of Health

Improving early diagnosis of cancer is a priority for this Government, and was clearly highlighted in the report Achieving World-Class Cancer Outcomes published last year by the Independent Cancer Taskforce. Earlier diagnosis makes it more likely that patients, including children with cancer, will receive effective treatments. We have committed to implementing all the recommendations of the Taskforce including that,

by 2020, everyone referred with a suspicion of cancer will receive either a definitive diagnosis or the all-clear within four weeks (28 days).

NHS England has the funds necessary to improve cancer services over the next five years, including up to £300 million by 2020 to support earlier diagnosis of cancer and the £10 billion of real terms increase in National Health Service funding by 2020-21. The recommendations in the Taskforce report give direction as to where these funds should be targeted.

In order to continue to support general practitioners (GPs) to identify patients whose symptoms may indicate cancer and urgently refer them as appropriate, the National Institute for Health and Care Excellence (NICE) published an updated suspected cancer referral guideline in June 2015. The guideline 'Suspected cancer: recognition and referral' includes new recommendations for childhood cancers.

NICE also addressed generally, non-site specific symptoms of concern in children and young people, recommending that GPs should take into account the insight and knowledge of parents and carers when considering making a referral for suspected cancer. NICE noted that more lives could be saved each year in England if GPs followed the new guideline, which encourages GPs to think of cancer sooner and lower the referral threshold.

HC Deb 19 October 2016 | PQ 48110

[Cancer: Children](#)

Asked by: Arkless, Richard

To ask the Secretary of State for Health, what steps his Department is taking to encourage a greater awareness of the (a) symptoms, (b) diagnosis, (c) research, (d) treatment and (e) support for the families of children affected by cancer.

Answering member: David Mowat | Department: Department of Health

Improving awareness and early diagnosis of cancer is a priority for this Government, and was clearly highlighted in the report *Achieving World-Class Cancer Outcomes (2015)* by the Independent Cancer Taskforce. Earlier diagnosis makes it more likely that patients will receive effective treatments. We have committed to implementing recommendation 24 of the report that by 2020, everyone referred with a suspicion of cancer will receive either a definitive diagnosis or the all-clear within four weeks. This standard will be underpinned by investment of up to £300 million more in diagnostics each year by 2020.

In order to continue to support general practitioners (GPs) to identify patients whose symptoms may indicate cancer and urgently refer them as appropriate, the National Institute for Health and Care Excellence (NICE) published an updated suspected cancer referral guideline in June 2015. The guideline, 'Suspected cancer: recognition and referral' includes new recommendations for childhood cancers. NICE also addressed generally, non-site specific symptoms of concern in children and young people, recommending that GPs should take into account the insight and knowledge of parents and carers when considering making a referral for suspected cancer.

The Department's National Institute for Health Research operates the UK Clinical Trials Gateway: www.ukctg.nihr.ac.uk. This publicly available website pulls through information about clinical trials and other

research from several different United Kingdom registers, including research on childhood cancers.

Over the last four decades there have been major advances in the development of successful treatment strategies for childhood cancers, and much of this has been due to the use of standardised protocols in clinical trials and centralisation of care. NICE Improving Outcomes Guidance for Children and Young People serves to assist National Health Service trusts in planning, commissioning and organising services for children and young people with cancer. It recommends, among other things, that all care must be provided in age-appropriate facilities. The treatment children receive will depend on the type of cancer they have, and the most common treatments include surgery to remove the tumour, chemotherapy and radiotherapy to destroy cancer cells, and stem cell and bone marrow transplants. In 2012, the Government provided £250 million to build two proton beam therapy centres in England (at University College London Hospital NHS Foundation Trust and The Christie NHS Foundation Trust in Manchester), the first of which will be fully operational in 2018.

The Government is working closely with cancer charities to ensure children get the support they need during and after their treatment. Last year we announced everyone diagnosed with cancer in England will benefit from an individually tailored recovery package by 2020, a key recommendation by the independent Cancer Taskforce. The recovery package, developed by Macmillan Cancer Support, will signpost people to rehabilitation and financial support services to help with the costs of cancer.

HC Deb 15 September 2016 | PQ 45983

[Cancer: Young People](#)

Asked by: Howarth, Mr George

To ask the Secretary of State for Health, with reference to the findings of the CLIC Sargent report, entitled Cancer costs: financial impact of childhood cancer revealed, published on 1 September 2016, if he will carry out an immediate review of travel assistance available to young cancer patients and their parents.

To ask the Secretary of State for Health, with reference to the CLIC Sargent report of 1 September 2016, entitled Cancer costs: financial impact of childhood cancer revealed, what assessment his Department has made of the effect of cancer on young people and their families.

Answering member: David Mowat | Department: Department of Health

We know that cancer can affect all areas of a person's life, including finances – 83% of people say they are financially impacted by cancer. People require holistic support from diagnosis onwards, encompassing their physical, financial, psychosocial, and information and support needs, throughout their entire cancer journey.

Children and teenagers with serious or critical illnesses such as cancer are also entitled to apply for Disability Living Allowance (DLA) (or a Personal Independence Payment if over 16). This is a tax free allowance, which contributes to the extra costs incurred by families in caring for children with additional needs and includes a mobility component. Children in receipt of DLA can receive up to £139.75 a week, and people who are terminally ill can have their claim fast tracked to access

benefits sooner. Families and carers can also qualify for Carer's Allowance and receive £62.10 a week if they meet the eligibility criteria, and some councils run Council Tax Reductions schemes for people on low incomes or who claim benefits.

We do not have any plans to review the hospital travel costs scheme – which provides financial assistance to those patients who do not have a medical need for ambulance transport, but who require assistance with their travel costs. This is part of the well-established NHS Low Income Scheme, in which patients on low incomes or receiving specific qualifying benefits or allowances can be reimbursed in part or in full for costs incurred in travelling to receive treatment at hospitals and this would include cancer treatment. It also can be claimed where the appointment has been made for a child or other dependent.

HC Deb 13 September 2016 | PQ 45001; PQ 45000

[Cancer. Children and Young People](#)

Asked by: Baroness Finlay of Llandaff

To ask Her Majesty's Government what discussions they have had with NHS England on the findings of CLIC Sargent's recent research report *The best chance from the start: improving support to identify cancer in children and young people*, including the finding that 53 per cent of young cancer patients asked felt their diagnosis was delayed.

To ask Her Majesty's Government what discussions they have had with Monitor and with NHS England about ensuring that GPs are able to access specialist expertise in children and young people's health, and what mechanisms they have to audit provision of specialist services and hold commissioners to account.

To ask Her Majesty's Government what discussions they have held in the last year with Health Education England about ensuring that all GPs gain experience in children and young people's health during their initial training, as suggested by CLIC Sargent's report *The best chance from the start: improving support to identify cancer in children and young people*.

Answering member: Lord Prior of Brampton | Department: Department of Health

Health Education England's (HEE) mandate sets out the Government's strategic priorities for workforce planning, education, training and development in the health and public health system. These objectives and priorities are published on an annual basis. Officials are currently discussing the next HEE mandate.

Within their three year training programme, about half of all General Practitioner (GP) trainees undertake a dedicated hospital placement in paediatrics. In addition, there are various initiatives around the country to increase access to child health training. These include clinics jointly staffed with paediatric and GP trainees, paediatric outreach clinics and multi-disciplinary meetings in GP surgeries led by paediatric consultants. A variety of e-learning, including the MindEd package – a free educational resource on children and young people's mental health, is available.

It is the responsibility of the General Medical Council (GMC) to set the standards and outcomes for the education and training of doctors and to approve training curricula to ensure newly qualified doctors are equipped with the knowledge, skills and attitudes to provide high quality patient care. HEE will work with bodies that set curricula such as

the GMC and the Royal College of General Practitioners to seek to ensure general practice training meets the needs of patients. The independent Cancer Taskforce published its report, *Achieving World-Class Cancer Outcomes* in July last year, which recognised the importance of earlier diagnosis for patients of all ages and contains specific recommendations for children, teenagers and young adults. NHS England has appointed Cally Palmer as NHS National Cancer Director to lead the implementation of a five year Strategy based on the recommendations in the report. Whilst the Taskforce was independent, the Department of Health and all of its Arm's Length Bodies were represented on it and contributed to development of the Strategy. NHS England is now developing its work programme to take forward the recommendations in the Strategy. There have been no discussions with Monitor as this falls outside their remit.

HL Deb 07 March 2016 | PQ HL6289; PQ HL6288; PQ HL6287

5.2 Adjournment Debate

[Childhood Cancers](#)

HC Deb 25 February 2015 | Vol 593 cc433-442

6. Useful links and further reading

Children's cancers – Macmillan Cancer Support

<http://www.macmillan.org.uk/cancerinformation/cancertypes/childrenscancers/childrenscancers.aspx>

Children with Cancer UK

<http://www.childrenwithcancer.org.uk/>

Children's cancers – Cancer Research UK

<http://www.cancerresearchuk.org/about-cancer/cancers-in-general/cancer-questions/childrens-cancers>

Children's Cancer and Leukaemia Group

<http://www.cclg.org.uk/>

CLIC Sargent cancer charity for children and young people

<http://www.clicsargent.org.uk/>

NICE Quality Standard *Cancer services for children and young people*
February 2014

<https://www.nice.org.uk/guidance/qs55>

CLIC Sargent *Cancer Costs: the financial impact of cancer treatment on young cancer patients and their families* September 2016

http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/CLIC%20Sargent%20Cancer%20Costs%20report%202016.pdf

The best chance from the start: improving support to identify cancer in children and young people February 2016

<http://www.youngpeopleshealth.org.uk/wp-content/uploads/2016/06/The-best-chance-from-the-start-report.pdf>

The independent Cancer Taskforce five-year plan *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020* July 2015

http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

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