



CHILDREN AND YOUNG PEOPLE'S CANCER SERVICES:

Ambitions for the next 10 years



About CLIC Sargent

Every day in the UK, 10 children and young people are given shocking news that will change their lives forever. They are told they have cancer. Treatment normally starts immediately, often happens many miles from home and can last for up to three years. A cancer diagnosis affects the whole family in many different ways

as the emotional, practical and financial implications can be intensely challenging.

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.

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June 2015

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Policy and influencing

CLIC Sargent works to raise awareness, influence change and help lessen the impact of childhood cancer. We undertake research into the impact of cancer on children and young people and use this evidence to raise awareness and to seek to influence government and policy makers, and those who provide public services across the UK, to help change things for the better for children and young people with cancer.

Young People's Health Partnership

CLIC Sargent is a member of the Young People's Health Partnership, a seven strong consortium of organisations working with the Department of Health, Public Health England and NHS England as strategic partners to raise the profile of the health agenda across the voluntary youth sector. For more information please visit www.clicsargent.org.uk/content/young-people's-health-partnership



FOREWORD



At CLIC Sargent we've set ourselves a challenge: to consider what the next 10 years might bring for children and young people with cancer, and to set a clear direction for our policy and influencing work.

Children and young people's cancer services: Ambitions for the next 10 years has been created to help inform our influencing work with policy makers and partners in the health and charity sectors to improve the cancer journey for children and young people. It has also informed the development of *Aiming high: our ambitions for children and young people with cancer*.

Our report is based on input from individuals with expertise in and experience of influencing the children and young people's health system at local, national and regional level. It describes their views,

perspectives and understanding of the current opportunities and challenges for the sector. It distils their hopes for the future of children and young people's cancer services into 10 clear ambitions for the next 10 years.

CLIC Sargent shares these ambitions for improving the support provided throughout children and young people's cancer journey. We hope to work with government, charities and the healthcare sector to help achieve them.

We'd like to thank all those who contributed to this report for their time, insights and invaluable expertise.

Lorraine Clifton

Lorraine Clifton
Chief Executive



INTRODUCTION

During the summer of 2014, CLIC Sargent interviewed experts from the health and social care sector, including those with specific expertise in the cancer journey for children and young people. These experts were:

- Dr Hilary Cass OBE, President, Royal College of Paediatrics and Child Health
- Dr Jackie Cornish OBE, National Clinical Director for Children, Young People and Transition, NHS England
- Mr Sean Duffy, National Clinical Director for Cancer, NHS England
- Kath Evans, Head of Patient Experience – Maternity, Newborn, Children and Young People, NHS England
- Dr Rachael Hough, Chair, Teenage and Young Adult (TYA) Cancer Clinical Reference Group and TYA Oncologist, University College London Hospital
- Dr Meriel Jenney, Consultant Paediatric Oncologist, Children's Hospital for Wales, Cardiff
- Pauline Leeson CBE, Chief Executive, Children in Northern Ireland and Co-Chair of the Children's Disability Strategic Alliance
- Christine Lenehan OBE, Co-Chair, Children and Young People's Health Outcomes Forum
- Dr Martin McCabe, Chair, National Cancer Intelligence Network (NCIN) Children, Teenagers and Young Adults Site Specific Clinical Reference Group
- Susan Morris, Chair, Wales Cancer Alliance
- Professor Kathy Pritchard Jones, Programme Director for Cancer, University College London (UCL)
- Anthony Prudhoe, Accountable Commissioner, Paediatric Cancer Clinical Reference Group and Programme of Care Lead, Women and Children (North Region)
- Professor Mike Stevens, Professor of Paediatric Oncology and Director, Macmillan ON TARGET
- Dr Hamish Wallace, Professor and Consultant in Paediatric Oncology, Edinburgh Royal Children's Hospital.

All job titles are stated as they were at the time of interview.

Approach

Interviews were carried out over the telephone and explored:

- Challenges for and concerns about the delivery of high quality health and care services for children, particularly those with conditions such as cancer
- Opportunities in the delivery of healthcare and current positive aspects
- Ambitions for health and care services for children and young people, particularly those with conditions such as cancer, and potential changes within the next 10 years
- The strengths and weaknesses in the delivery of health and social care services to children and young people throughout their cancer journey
- Foreseeable changes to treatment within the next decade.

The content of each interview was analysed to generate themes. Quotes expressing individual views were extracted and feature throughout this report.

The list of contributors does not represent an exhaustive list of all those who have experiences and insight relevant to

this debate. This report aims to set the ground work and identify key themes for ongoing work to engage in debate and influencing activity with experts from the health and social care sector, particularly those with specific expertise in the cancer journey for children and young people.

Ambitions for the next 10 years: in summary

We have brought together the views expressed by our expert contributors during these interviews to identify the following 10 ambitions for what the cancer journey for children and young people might look like in 10 years' time:

1. Improved routes to diagnosis
2. A health system which supports resilience in children and young people with cancer
3. Effective national and network commissioning
4. Increased specialisation of treatment and care
5. Service and treatment innovations
6. More access to safe care closer to home
7. Better support after treatment
8. Greater recognition of the value of a young person-specific approach
9. Increased access to data
10. Clear accountability for service delivery and improving outcomes.

This report provides an overview of the current cancer journey for children and young people across the UK, and goes on to explore the key themes which underpin these 10 ambitions for improvement. The themes have UK-wide relevance, and any issues specific to England, Northern Ireland, Scotland or Wales are highlighted.

CHILDREN AND YOUNG PEOPLE'S CANCER SERVICES: THE CURRENT PICTURE

Cancer in children and young people

Key facts:

- Every year in the UK around 3,800 children and young people under 25 are diagnosed with cancer
 - There are almost 26,600 children and young people in the UK currently living with a cancer diagnosis¹
 - Although eight in 10 will survive cancer, it is still the leading cause of death overall from disease among children and young people in the UK²
 - The types of cancer which affect children are different from those that affect adults.
- They occur in different parts of the body and respond differently to treatment³
- The majority of young people experience one of a small group of cancer types that are relatively rare in the overall population, but common for young people. A minority develop one of the cancer types which are more typical of older adults⁴
 - Some groups of children and young people who survive cancer are at an increased risk of physical, psychological and social health problems following treatment or later in life (often referred to as 'late effects').⁵

The journey through health services

The path that children and young people with cancer take from diagnosis, during treatment and into life after treatment is often referred to as their 'cancer journey'.

Diagnosis

In most cases, children and young people with cancer are diagnosed via referral to specialists by their general practitioner (GP) or by a hospital Accident and Emergency (A&E) department.

In England, children and young people are more likely than older adults to be diagnosed with cancer through emergency presentations, such as at A&E. Between 2006 and 2010, 23% of cancer patients of all ages were diagnosed through emergency presentation, whereas 53% of 0 to 15-year-olds and 37% of 16 to 24-year-olds were diagnosed this way.⁶

In older cancer patients, there is an assumption that emergency presentations are associated with worse outcomes. However, in children and young people, research has yet to be conducted to establish clearly whether emergency presentation is associated with poorer outcomes or whether these high percentages relate to factors which are specific to particular cancer types experienced by children or young people, or the way in which they and their families access health services.

Treatment centres

Specialist inpatient care for children and young people with cancer in the UK is provided by principal treatment centres (PTCs) as follows:

- On suspicion of cancer, all children with cancer aged 0 to 15 must be referred to a PTC
- On suspicion of cancer or after diagnosis, young people aged 16 to 18 must be referred to a teenage and young adult (TYA) PTC which provides age appropriate care

Multi-disciplinary teams

During treatment at a PTC, cancer care for children and young people must be directed by multi-disciplinary teams (MDTs). The MDT approach has been developed to encompass the complex range of services required for children and young people with cancer.

Treatment for cancer is often physically and emotionally gruelling. It can have a wide range of additional impacts such as feelings of isolation, and barriers to participation in education, training and employment. Families of children and young people with cancer are likely to experience emotional strain, as well as practical concerns such as arranging time off work and providing care for both a child or young person in hospital and any siblings at home. Consequently, MDTs include a combination

Accommodation

NHS provided accommodation available for families of children and young people with cancer who are receiving treatment at a PTC varies widely. In some parts of the country accommodation is provided by charities to ensure that when a child or young person is receiving treatment at a PTC which is a long way from their home, their families have a safe and supportive place to stay.

- After diagnosis, those aged 19 to 24 should be offered the choice to be referred to a hospital which offers age appropriate care, but many are treated in local hospitals within adult cancer wards.

When CLIC Sargent surveyed families of children with cancer in 2010, 77% of those who responded did not live in a city with a PTC, and were travelling an average of 60 miles, up to five times a week, for hospital treatment.⁷

of professionals who determine clinical care, such as oncologists, haematologists, pharmacists, etc and those who provide emotional and practical support to children, young people and families, such as social workers, psychological services professionals or play therapists. A MDT is likely to have a core membership, eg as a solid tumour MDT or a leukaemia MDT, and an extended membership to meet the individual needs of a child or young person. This extended membership might include physiotherapists, dietitians, psychotherapists, etc.

Funding for some MDT posts may be partly or fully provided by charities, for example, CLIC Sargent funds social workers who work within MDTs for children and young people with cancer.

CLIC Sargent provides this in the form of 'Homes from Home', which offer free self-catering accommodation, close to hospitals, for families during inpatient treatment and to enable children and young people to receive treatment on an outpatient/day care basis.

Treatment closer to home

Treatment can be delivered entirely within a PTC. However, in some parts of the UK, PTCs have a 'shared care' partnership with a paediatric oncology shared care unit (POSCU) or designated TYA treatment centre in a hospital which can provide aspects of treatment closer to a child or young person's home.

According to NICE Improving Outcomes for Children and Young People with Cancer guidance, shared care arrangements should include an identified lead clinician and lead nurse, clinical protocols

should be approved for treatment and care, and areas of responsibility in relation to PTCs should be defined.

Geographically, shared care for children and young people with cancer is not consistently accessible across the UK.

A map of PTCs, POSCUs and designated TYA treatment centres across the UK is available on the CLIC Sargent website: www.clicsargent.org.uk/in-my-area.

Post-treatment

Following treatment, the consultant responsible for the child or young person's care should direct an 'aftercare pathway' and provide long-term follow-up to manage

the late effects of treatment in coordination with local community services. This may also include transition to adult services.

When cure is not possible

When a child or young person cannot be cured, they are likely to access palliative and end of life care support. This part of the journey may involve different MDT members and have a greater community focus. The role of the outreach nurse using a key worker model of care is vital at this stage. There may also be links to hospice services where these are available and acceptable to the family. Access to this kind of support for

young people is often more limited than it is for children, as there is less age appropriate community and hospice care available. This is particularly the case for the 16 to 18 age group because they fall beyond the age limit for paediatric palliative care services, but are not yet old enough to access adult palliative care teams and hospices.

AMBITIONS FOR THE NEXT 10 YEARS: IN DETAIL

This section summarises the views of the expert contributors to this report. Their perspectives illustrate and underpin 10 ambitions for what cancer services for children and young people might look like in 10 years' time.

1. Improved routes to diagnosis

During interviews for this report, the need to improve the ways in which cancer in children and young people is diagnosed was highlighted as a major priority within the NHS across the UK. It was felt that a more detailed understanding of the optimum routes to diagnosis for cancers in children and young people is required. Lack of research on the causes and impact of delayed diagnosis for this age group was a key area of concern. The emotional impact of delayed diagnosis on families was also emphasised.

"Delayed diagnosis is an issue in the UK, both in terms of patients presenting to primary or secondary healthcare and doctors identifying that their symptoms might be due to cancer. It is certainly a current area of weakness that we don't have good evidence on routes to diagnosis. However, we do know that children, young people and parents are very upset and distressed when they have been seen several times in primary and secondary care and feel like they haven't been listened to." Dr Martin McCabe, Chair, National Cancer Intelligence Network (NCIN) Children, Teenagers and Young Adults Site Specific Clinical Reference Group

Identifying and diagnosing cancer in children and young people was highlighted as a challenging area for primary care in the UK. Although care of children is part of the core curriculum objectives for the GP training programme, training in hospital-based paediatrics is not mandatory for GPs.⁸ This is thought to result in less than half of GP

trainees receiving in-hospital paediatric experience, which would provide them with the opportunity to learn how to identify and care for children who are unwell.⁹ The Royal College of GPs (RCGP) Child Health Strategy 2010–2015 states that: *'The RCGP feels that GP training is too short and should be extended from three to five years. Whilst the majority of GP trainees do manage to spend 18 months in general practice during training, where they will see a lot of children presenting to them, there are many who still only get one year.'*¹⁰

It was suggested that primary care professionals in the UK need better access to support and training, both initial training and ongoing development opportunities, to help them to engage effectively with children and young people, and to confidently identify potential cancer diagnoses in this age group.

"I know that the Royal Colleges are looking at this, but it would be beneficial to get more paediatric expertise into front line primary care." Professor Kathy Pritchard Jones, Programme Director for Cancer, University College London (UCL)

Finally, it was suggested that financial drivers within primary care should be examined, such as the Quality Health and Outcomes Framework voluntary annual reward and incentive programme for all GP surgeries in England. There were concerns that these mechanisms do not adequately reward best practice in meeting the needs of children and young people.

2. A health system which supports resilience in children and young people with cancer

Recent research by CLIC Sargent demonstrates the benefit of conceptualising resilience as an outcome: the outcome of successfully coping with stressful experiences. The literature on resilience and experts in the field often link it to notions of coping and competence, and there is evidence of a range of effective approaches to building resilience.¹¹

It was mentioned that in order to improve holistic long term outcomes, the NHS should adopt and promote the concept of supporting resilience as an underpinning principle for working with children and young people with cancer throughout the UK. It was felt that this would require a culture shift, challenging traditional attitudes and models of care.

"I think what we should be promoting is resilience and self-care in our young people and their families. The historical model is 'we will take care of you, we will surround you with compassion and care'. It is an excellent model for the short term, but is it the best one for promoting resilience and self-care in the longer term? What we are less good at is saying 'ok, this is tough, but we can give you the resource and information you need during your treatment and when you are moving on.'" Professor Mike Stevens, Professor of Paediatric Oncology and Director, Macmillan ON TARGET

It was felt that both individual and community approaches to resilience are relevant to children and young people with cancer. Best practice in promoting resilience in individuals,

delivered by charities as part of PTC MDTs and through outreach and community-based support, was highlighted. Approaches taking the wider health and social care system into account were also acknowledged.

"Charities are wonderful as they do individual work with children, young people and their families, and they also see them as part of a bigger network of support in terms of school, friends and the community." Pauline Leeson CBE, Chief Executive, Children in Northern Ireland and Co-Chair of the Children's Disability Strategic Alliance

3. Effective national and network commissioning

NHS commissioning for children and young people's cancer services

Children and young people's cancer services are commissioned and coordinated discretely within each of the UK's four nations.

In England, the Health and Social Care Act 2012 introduced national specialised commissioning and brought about the conversion of clinical networks, including cancer networks, into Strategic Clinical Networks in 2013. It was argued that time is needed to ensure that long-established good practice is transferred to new structures within the health service.

The commissioning of cancer treatment for children and young people in Scotland is coordinated through the Managed

Service Network, which has been in place since 2012 and was described positively. Changes and site moves within two Scottish PTCs were noted as an area of interest, which will require the engagement of key partners such as the voluntary sector.

It was suggested that Northern Ireland experiences a variation in service provision due to the number of health trusts. Similarly, variation between the number of health boards in Wales was considered to be a possible barrier to ensuring equality of access to good service provision, requiring better national coordination and leadership for cancer services.

National standards

The critical importance of national and network specialised commissioning for children and young people's cancer services in ensuring quality throughout the cancer journey was highlighted. In particular, it was felt that national standards and service specifications were essential.

"Service specifications give us the opportunity to ensure the safety of the entire pathway for children and young people with cancer through best practice guidelines." Dr Jackie Cornish OBE, National Clinical Director for Children, Young People and Transition, NHS England

The impact of and uncertainty about the wider financial context on NHS specialist services was highlighted. For example, it was

felt that access to information and data on current NHS England spend on specialised services for children and young people with cancer would be useful in helping to assess the way in which the broader financial challenge may have implications for children and young people's cancer services.

It was also emphasised that national decision makers and commissioners would benefit from a better understanding of the role of the charity sector in ensuring that standards and service specifications for children and young people with cancer in the UK are delivered. It was felt that the NHS should both acknowledge this and seek to appropriately involve charities when planning and commissioning services.

Local commissioning

It will always be necessary for local areas to commission certain services that children and young people with cancer access both during and after treatment. It was suggested

that there can be uncertainty about the commissioning responsibilities within local areas, such as for Clinical Commissioning Groups in England in terms of children

and young people returning from cancer treatment at a PTC. This can mean that the transition between the PTC and the child or young person's local community is not as

smooth as it could be, and responsibility for service provision to meet ongoing health and social care needs for those who have, or have had, cancer is not always well understood.

4. Increased specialisation of treatment and care

Further specialisation of treatment in fewer centres is currently a major topic for debate within cancer services in the UK. Putting Patients First, the 2014/15 to 2015/16 NHS England Business Plan, included an objective to consider how many specialised centres will be required in future and how they should be geographically distributed to maintain access. The NHS England Five Years Forward View, published in October 2014, states that:

*'In some services there is a compelling case for greater concentration of care. In these services there is a strong relationship between the number of patients and the quality of care, derived from the greater experience these more practiced clinicians have, access to costly specialised facilities and equipment, and the greater standardisation of care that tends to occur. For example, consolidating 32 stroke units to eight specialist ones in London achieved a 17% reduction in 30-day mortality and a 7% reduction in patient length of stay. The evidence suggests that similar benefits could be had for most specialised surgery, and some cancer and other services.'*¹²

The potential benefits of treatment within more specialised centres of excellence for children and young people with cancer were acknowledged by contributors.

"I think if you asked patients it would be critically important to them that they felt they were getting the best possible treatment. I think there are some benefits to be gained from centralising, where there is evidence that it can improve outcomes." Dr Meriel

Jenney, Consultant Paediatric Oncologist, Children's Hospital for Wales, Cardiff

It was suggested however that moves to create fewer specialised centres would be likely to result in the need to make difficult decisions. While increasing specialisation and reducing the number of centres may lead to better quality treatment and improved outcomes, there would be an impact on families travelling long distances and staying away from home. Young people in particular may not have the means to travel, which will mean that their ability to choose their place of care is limited.

Consequently, it was felt that children and young people should be considered in national planning of further specialisation in cancer treatment, so that the introduction of site or treatment specific specialism does not disrupt care delivery and MDT support.

"One area of concern is that if there is increasing centralisation, there is a risk that it may dislocate condition specific treatment from children and young people's cancer services. For example, if the aim is to reduce the number of transplant centres, can we be sure that that will be done with coherence of the children and young people's cancer pathway in mind?" Rachael Hough, Chair, Teenage and Young Adult (TYA) Cancer Clinical Reference Group and TYA Oncologist, University College London Hospital

5. Service and treatment innovations

Clinical trials

Some children and young people with cancer take part in clinical trials. This was seen as beneficial to individual patients and as a way to develop better treatment.

"In moving forward, underpinning recruitment for clinical trials for children and young people will be very important, not only as a development goal so that we can best treat cancers that affect different age groups, but because of the quality of care provided to those on clinical trials." Sean Duffy, National Clinical Director for Cancer, NHS England

The relatively high level of recruitment to children's cancer clinical trials was seen as a major strength of the current UK system, but an increase in these numbers was seen as a key aim.

"Certainly the direction of travel is to have all children on clinical trials - and that is quite a distance from where we are now." Anthony Prudhoe, Accountable Commissioner, Paediatric Cancer Clinical Reference Group and Programme of Care Lead, Women and Children (North Region)

Serious concerns were raised that teenagers and young adults with cancer are less likely to have access to clinical trials.

Treatment innovations

It was felt that innovations in treatment have the potential within the next 10 years to increase survival rates, minimise the damage of treatment and improve long term health outcomes for children and young people with cancer.

Gaining greater insight into the physiological impact of cancer treatment on children and young people was a key goal. It was suggested that a better understanding of

"Recruitment of young adults to trials drops off dramatically. The reasons for this are not well understood, but one factor is that many young people with cancer are treated at centres that don't have appropriate clinical trials open." Dr Martin McCabe, Chair, National Cancer Intelligence Network (NCIN) Children, Teenagers and Young Adults Site Specific Clinical Reference Group

It was suggested that there has been recent success in demonstrating the value of trials for this age group to the cancer community and health service, and that this could help to increase access and generate research that has a demonstrable impact on outcomes.

Involving children, young people and parents in research was also seen as key. This could range from involvement in identifying research priorities to working in partnership with researchers to design appropriate methodologies and trial recruitment strategies.

"We are likely to see parents playing a part in designing studies in order to help to maximise recruitment and to make the whole delivery of a clinical trial more family friendly." Professor Kathy Pritchard Jones, Programme Director for Cancer, University College London (UCL)

biological factors could help to develop more individualised treatments and reduce toxicity.

"If we want to not only cure people but to limit the physical impact of treatment on them, then we need to understand toxicity better." Dr Rachael Hough, Chair, Teenage and Young Adult (TYA) Cancer Clinical Reference Group and TYA Oncologist, University College London Hospital

It was also suggested that insights into genetics will bring about innovation.

“For many cancers in this age group we know the genetic targets that we need to aim for, but we haven’t had access to drugs that work against them. That is now starting to change and with sustained investment in biological research, in drug development

and in clinical trials in this age group, we should be optimistic that in 10 years’ time we will have a much larger range of targeted drugs than we do at present for our patients.” Dr Martin McCabe, Chair, National Cancer Intelligence Network (NCIN) Children, Teenagers and Young Adults Site Specific Clinical Reference Group

6. Greater access to safe care closer to home

As so many children and young people do not live in a city where there is a PTC, services have been created to provide support to help them to spend as much time as possible at home during their treatment. This is critically important in preventing

them from feeling isolated from their family, friends and community, ensuring they are able to continue to access education, employment or training and minimising the practical strain on their families.

Shared care

Access to ‘shared care’ between PTCs and hospitals closer to children and young people’s homes is not uniform across the UK. Designated shared care hospitals are well developed in the south of England, the Midlands and East Anglia, and there are clusters in North Wales and Scotland. However, elsewhere in the UK there are gaps in the provision of shared care, and this can be particularly problematic for families who have to travel considerable distances to their PTC. There are also regional and local variations in how shared care is funded. Some trusts are able to use cancer tariffs, and some use a general paediatric tariff. This can lead to loss of comparable access to services offered in shared care.

It was felt that there is scope for improvement in the provision of shared care over the next 10 years, as long as those infrastructural challenges are addressed.

“I think one opportunity is to look again at the distribution of shared care. How do we make sure this is set up in a way that will reduce disruption to life, and will reduce cost? How do we ensure that patients get good care and support locally, but they are within the reach of the PTC to make sure they are getting the right treatment?” Dr Rachael Hough, Chair, Teenage and Young Adult (TYA) Cancer Clinical Reference Group and TYA Oncologist, University College London Hospital

Specialist outreach nurses, social workers and the key worker model of care

Highlighted in particular was the vital importance of specialist outreach nurses, particularly paediatric oncology outreach nurses in helping to provide care closer to home and in helping schools to support children and young people to access education during treatment.

“With more nurses there could be more blood samples taken from home, and fewer clinic visits for the children.” Dr Hamish Wallace, Professor and Consultant in Paediatric Oncology, Edinburgh Royal Children’s Hospital

Variable numbers of specialist outreach nurses across the country and the potential threat of the financial climate to those roles was raised as an area of concern.

"We need to recognise the significant difference that nurse specialists make in terms of enhanced experiences for children and young people and their families, particularly in a financial climate where the provision of these roles is challenged and yet we know that they make such a difference." Kath Evans, Head of Patient Experience - Maternity, Newborn, Children and Young People, NHS England

Social workers and nurses who provide key worker support were described as

vital as they help to coordinate care in partnership with families and young cancer patients. The value of the charity sector in providing these services was expressed.

"There is a reliance on the charity sector to supply social workers, outreach nurses, key workers and many of the other staff that make up childhood and adult cancer services. When the commissioning arms of the NHS make funding decisions they should bear in mind that many of the services deemed to be core functions of these specialist services are funded by charities." Dr Martin McCabe, Chair, National Cancer Intelligence Network (NCIN) Children, Teenagers and Young Adults Site Specific Clinical Reference Group

Community provision

Contributors were concerned about capacity within local communities to respond when a child or young person with cancer returns to their area from a PTC. It was suggested that commissioners needed to focus more on the importance of community nurses for children and young people. It was also felt that primary care and community health professionals should have access to specialist

training and support materials when a child or young person in their community has cancer.

"Nursing and medical staff need access to high quality post-registration education and training so that they can actually deliver the very best levels of care, when appropriate, within a child or young person's community." Kath Evans, Head of Patient Experience - Maternity, Newborn, Children and Young People, NHS England

Self-directed care

The notion of self-directed care at home was flagged as an opportunity to enhance existing provision and to empower children, young people and their families. Some contributors highlighted the role of technology to enable this. Suggestions included the use of video chat software such as Skype within interviews and email support, reducing the need for travel.

"I think there is massive scope in IT to give children and young people, and their families, much better ownership of information.

This would not just be about their conditions, but on the day to day monitoring of their condition. It could bring much better connectivity between the PTC, the hospital delivering shared care and community health services. It could allow easier ways for families to message in to their care providers and doctors. Apart from the fact that this will empower patients, it will be a much more cost effective approach for the NHS." Dr Hilary Cass OBE, President, Royal College of Paediatrics and Child Health

7. Better support after treatment

Assessment and planning

Assessment and planning for aftercare and support should be a key part of a treatment plan. It was felt that when a child or young person is in treatment, preparations should be made for care after treatment, as well as ongoing monitoring and surveillance.

"One of the key things in survivorship is to deliver really good assessment and care planning, and making sure that people get the information they need. There must be a proper assessment of their holistic needs,

including education and broader social needs. There also needs to be a cultural shift so that children and young people, and their families, have the information they need to care for themselves." Susan Morris, Chair, Wales Cancer Alliance

However, there were concerns about the inconsistency of assessment and planning, with children and young people with cancer receiving a variable level of service in terms of end of treatment summaries and care plans.

Ongoing support for cancer survivors

Not all children and young people who experience cancer have ongoing specialist care needs. However, contributors referred to a lack of coherency in addressing the ongoing needs of children and young people who have had cancer, even in circumstances where there are clear indications that further support will be required.

"How do we actually make sure that patients who have been cured of cancer get the right care when they are not

actually at risk of their cancer relapsing but maybe have an associated health condition?" Dr Hamish Wallace, Professor and Consultant in Paediatric Oncology, Edinburgh Royal Children's Hospital

One key issue identified was that of long-term follow-up within adult services for those who survived cancer as a child or young person. Uncertainty about the availability of appropriate support was expressed.

Palliative and end of life care

As with shared care and support from specialist nurses, access to palliative and end of life care is subject to geographical and age-based inequity. Furthermore, concerns were raised about workforce challenges that will put palliative care services under more pressure.

"I am really concerned that we don't have sufficient numbers of young doctors applying for training in paediatric palliative care. We also need to look at training up many more paediatricians, GPs and nurses to

develop stronger skills in paediatric palliative care, even if it is not their main specialty." Dr Hilary Cass OBE, President, Royal College of Paediatrics and Child Health

A lack of provision for teenagers and young adults with cancer was also highlighted. Concerns were raised that paediatric services are provided for under-16s, and adult services are provided from 18, but it is much more difficult to set up palliative care for those between 16 and 18.

8. Greater recognition of the value of a young person-specific approach

Contributors felt that the TYA MDT approach to treatment and care for 16 to 24-year-olds with cancer has helped to create a young person-specific model of care which has challenged the traditional view of this age group as merely a 'transition' group. It has allowed health services and charities to respond to the specific needs of young people at this crucial developmental time, generating lessons applicable to the wider health service.

However, while progress has been made, it was suggested that a young person-specific model or culture is not embedded across the NHS. There were concerns that information provision about treatment settings may be limited, with choices not presented as equally valid. Some contributors were worried about professional and financial biases towards

retaining a young person within the setting in which they present. This could mean that the option of treatment at a PTC may be depicted as involving unnecessary travel to receive what could be delivered in a local hospital.

It was also acknowledged that particular challenges remain in terms of provision of care closer to home and support after treatment for young people at the age where transition between children and adult services occurs. This is an area where geographical difficulties are prominent.

"Some places have got superb transition and specific facilities for young people crossing that age range between 16 into early 20s, but some people are not doing transition as well - it is highly variable around the country." Dr Hilary Cass OBE, President, Royal College of Paediatrics and Child Health

9. Increased access to data

Lack of data collection and monitoring of outcomes

Contributors suggested that limited access to data is a barrier to improvement in children and young people's cancer services.

One example of this is lack of data on location and quality of treatment and care for young people with cancer.

"We have poor access to data on how many young people are being treated, where they are being treated, if their care is appropriate, what their outcomes are, etc. Without this information, how can you ensure that patients are on the right pathways and getting the right treatment, and how can you improve outcomes?"

Dr Rachael Hough, Chair, Teenage and Young Adult (TYA) Cancer Clinical Reference Group and TYA Oncologist, University College London Hospital

It was felt that improved care quality monitoring across the UK should enable the comparison of outcomes nationally and internationally, for cancer in general and for children and young people specifically. It was suggested that the new Cancer Outcomes and Services Dataset (COSD) provides an important opportunity to analyse data on every patient diagnosed with cancer, including the spread of the disease and demographic information on where patients are treated. However, this included a caveat that focus must be given to ensuring that COSD and other data collection mechanisms are well understood and consistently used by those with responsibility for them.

Respecting and responding to the views and experiences of children with cancer and their families

Patient experience is increasingly central to the monitoring of health services and to the way in which strategic and service level priorities for improvement are established. However, where surveys of patient experience for those with cancer exist in the UK, they only capture the experiences of those who are aged 16 and above. In addition, although a NICE guideline exists on patient experience for adults, there is not an equivalent guideline for children and young people.

Serious concerns were raised that without evidence of how children younger than 16 are experiencing services, it is difficult to ensure those services are truly responsive and tailored to their needs and preferences. Lack of monitoring, it was suggested, equates to a system which lacks transparency and accountability.

"We don't have the national cancer patient experience survey for children, so it is not transparent enough in terms of monitoring." Anthony Prudhoe, Accountable Commissioner, Paediatric Cancer Clinical Reference Group and Programme of Care Lead, Women and Children (North Region)

It was noted that NHS England is looking seriously at this issue and that it will require careful consideration and design.

"The challenge is not only to establish a set of questions which will help us to effectively understand the experience of children with cancer, and their parents where appropriate, but also to align the questions to the levers that might create improvements based on the data collected." Sean Duffy, National Clinical Director for Cancer, NHS England

10. Clear accountability for service delivery and improving outcomes

Embedding a strategic focus on children and young people within the NHS

In order to improve the cancer journey for children and young people over the next 10 years, a stronger strategic focus within the NHS and clear accountability for the outcomes of all children and young people is required.

"There is a lack of understanding of where ultimate responsibility lies for improving children and young people's outcomes

within the NHS as a whole. It is crucial that charities who represent the interests of children and young people within the NHS continue to push for greater accountability for improved outcomes, and for clearer systems of integration, for example between primary and secondary care." Christine Lenehan OBE, Co-Chair, Children and Young People's Health Outcomes Forum

A strong voice for children and young people with cancer

Cancer plans and policy frameworks in each of the UK nations have made cancer a strategic priority for the health service. However, contributors felt that the needs of children and young people have not always been well served within these plans, and action to improve services for them

has not been sufficiently differentiated from action to address the needs of older adults. It was felt that there are currently opportunities to make positive progress in this area, as new cancer strategies and plans are developed in each of the UK nations.

Consequently, the need for a strong voice on key priorities for improvement in children and young people's cancer services within the NHS in the UK was acknowledged. It was felt that this voice must be heard at a national, regional and local level, and continue to be reinforced by the charity sector and experts within the health system itself. A challenge was issued to those working in the charity sector to act as advocates for children and young people, and to use their networks, contacts and influence to promote the value of their cause.



ACHIEVING THESE AMBITIONS

We're very grateful to the expert contributors who shared their knowledge and expertise with us. We've reflected on the information that they provided and believe it offers a clear set of priorities for the charity sector, the NHS and to governments across the UK to move forward in creating a better cancer journey for children and young people.

Progress in 2014/15

Since 2014 there have been some significant developments in cancer policy. In Wales, the Health and Social Care Committee has published a report into the implementation of the Wales Cancer Delivery Plan Together for Health. In both England and Scotland, Cancer Taskforces have been working with stakeholders to formulate new Cancer

Strategies for the NHS. In England, Dr Jackie Cornish OBE; National Clinical Director for Children, Young People and Transition, NHS England, is chairing a working group which will consider the services delivered throughout the cancer journey for children and young people and will feed into the Cancer Taskforce.

Priorities for NHS and government action

In light of these developments, we are hopeful that NHS leaders in England, Northern Ireland, Scotland and Wales will ensure that there is a defined children and young people's strand within their cancer plans with clear monitoring and accountability measures. In order to help us to achieve the ambitions set out in this report, these plans should:

- Establish ways to improve diagnosis for children and young people with cancer through:
 - Investment in research which helps to provide an evidence base on optimum routes to diagnosis for children and young people with cancer, and the impact of delayed diagnosis on survival and outcomes
 - Improved access to training, support and information for primary care professionals to help them to better identify and diagnose children and young people with cancer.
- Create a change programme within NHS cancer services in each of the UK nations to move toward a cancer journey which promotes resilience in children and young people with cancer through support, information and advice as part of a holistic approach to help them to cope with adversity
- Protect effective commissioning and provision of specialist care by introducing a 'children and young people' test, which is applied when changes are made to specialised commissioning and the provision of specialised centres of excellence
- Move towards more equal provision of safe care closer to home across the UK by undertaking an evaluation of the current state of access to safe, high quality care closer to home for children and young people with cancer and working with charities to establish resourcing and provision required to address areas of inequality

- ◉ Address system barriers which prevent access to support after treatment and palliative care for children and young people with cancer, particularly those aged between 16 and 18
- ◉ Take action to improve data on place of treatment and related health and wellbeing outcomes for young people with cancer, and to assess whether NICE guidelines on provision of choice of age-appropriate care are effectively implemented
- ◉ Ensure that data is effectively collected on patient experience for children and young people with cancer - for example by extending national cancer

patient experience surveys to children under 16 - and publish action plans to improve experience based on findings

- ◉ Establish accountability for improving outcomes for children and young people with cancer within national cancer plans, and commit to publishing transparent information on progress.

We urge the UK government, and the governments of Northern Ireland, Scotland and Wales, to work with health and social care policy makers, NHS leaders, charities and children and young people with cancer, and their families, to help make this happen.

Priorities for CLIC Sargent

In order to contribute to this, CLIC Sargent will:

- ◉ Provide platforms for debate and discussion on how to address key challenges for the children and young people's cancer sector, based on the ambitions set out in this report
- ◉ Undertake an influencing campaign that seeks to provide more detailed insights into the key issues of those we support, and to explore policy and practice solutions that could improve children and young people's cancer journey
- ◉ Act as patient representative on behalf of the children and young people with cancer we support within the NHS and policy settings - for example, as part of the Clinical Reference Groups for paediatric cancer and teenage and young adult cancer in England
- ◉ Increase the support we provide to children and young people with cancer through the implementation of CLIC Sargent's 2015 to 2025 strategy *Aiming high: our ambitions for children and young people with cancer*

- ◉ Continue to develop and promote models of good practice, such as:

- the CLIC Sargent Key Worker project, for which an evaluation report will be published in June 2015
- the CLIC Sargent Key Worker Education project in Scotland, which will provide a web based education and information tool, and could be adapted and made available to contribute to UK wide access to support safe care closer to home
- the CLIC Sargent Young People's Community Worker model, which has established a good practice service model for young people with cancer aged 16 to 24, offered in the community and based around education/employment and providing support to resume or maintain life outside/beyond cancer.

REFERENCES

- ¹ National Cancer Intelligence Network and Macmillan (2013)
www.ncin.org.uk/about_ncin/segmentation
- ² Data taken from Cancer Research UK (accessed Jan 2015)
www.cancerresearchuk.org/cancer-info/cancerstats
- ³ NHS England, 2013/14 *NHS Standard Contract for Paediatric Oncology*
www.england.nhs.uk/wp-content/uploads/2013/06/e04-paedi-oncol.pdf
- ⁴ NHS England, 2013/14 *NHS Standard Contract for Cancer: Teenagers and young adults*
www.england.nhs.uk/wp-content/uploads/2013/09/b17.pdf
- ⁵ Data taken from Cancer Research UK (accessed Jan 2015)
www.cancerresearchuk.org/cancer-info/cancerstats
- ⁶ National Cancer Intelligence Network, *Routes to Diagnosis Workbook 2006-2010*
- ⁷ CLIC Sargent (2010), *A long way from home*
- ⁸ Royal College of General Practitioners (2010), *RCGP Child Health Strategy 2010-15*
- ⁹ NHS Future Forum (2012), *Education and Training - next stage. A report from the NHS Future Forum, cited from: Report of the Children and Young People's Outcomes Forum*
- ¹⁰ Royal College of General Practitioners (2010), *Child Health Strategy 2010-2015*
- ¹¹ CLIC Sargent (2014), *Coping with cancer: Supporting young people's resilience*
- ¹² NHS England (2014), *NHS Five Year Forward View*

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CHILDREN AND
YOUNG PEOPLE
WITH CANCER**

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Registered charity number in England and Wales: 1107328
Registered charity number in Scotland: SC039857
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