



THE BEST CHANCE FROM THE START

Improving support to identify cancer
in children and young people

A CLIC Sargent report
www.clicsargent.org.uk



SUMMARY

The best chance from the start explores the experiences of young cancer patients and parents of finding out that they, or their child, had cancer, with a particular focus on their experiences of primary care. It also provides an insight into some of the barriers that GPs face in identifying suspected cancer in children and young people. This report aims to raise awareness among government and NHS policy makers, health and care professionals and the voluntary sector, of the way in which diagnosis of cancer in children and young people could be better supported in the UK health system.

ABOUT CLIC SARGENT

CLIC Sargent's mission is to change what it means to be diagnosed with cancer when you're young. We believe that children and young people with cancer have the right to the best possible treatment, care, and support, throughout their cancer journey and beyond. And they deserve the best possible chance to make the most of their lives once cancer treatment has ended.

CLIC Sargent provides vital emotional, practical and financial support to young cancer patients and families during and after treatment, and we take what they tell us about the impact of cancer on their lives to service providers and policy makers to help change things for the better.

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February 2016

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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 influence government, 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



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. CLIC Sargent brings the views of the young cancer patients we work with into the partnership's work programme and activities, so that we can influence policy makers on their behalf.

FOREWORD



Being diagnosed with cancer is a frightening experience. When the person being diagnosed is a child or a young person, it is

particularly shocking. The ramifications for both the individual and their family are profound.

At CLIC Sargent we know that when a child or young person has cancer, one of the most important things that the health system can do is to give them a diagnosis as early as possible, and take swift action to provide treatment. Yet, parents and young people often tell us that their journey to diagnosis was far from straightforward.

Too often, they tell us that delays to diagnosis, challenges for GPs in recognising that symptoms may be related to cancer and the feeling that they are not being listened to or taken seriously when reporting concerns left them stressed and frustrated during an already deeply distressing time. Worryingly some have suggested that a delay to their diagnosis may have resulted in poorer long term outcomes.

The current evidence base does not tell us everything we need to know about the routes to diagnosis which children and young people with cancer experience, and its impact on their outcomes. This makes the improvement of services all the more difficult. We therefore undertook this

research in order to bring together what is known, and to try and address some of the gaps.

Cancer in children and young people is thankfully rare. However, this means that professionals in primary care, such as GPs, may only see one or two cases during their career. Recognising the symptoms, which are not always obvious, can be difficult. At CLIC Sargent, we want professionals in primary care to have the best possible support in identifying suspected cancer in children and young people.

We are hugely grateful to the young people, parents and health and social care professionals who took part in our research. Their stories paint a mixed picture: while some experienced the very best that our health service has to offer, others had a more difficult and upsetting time.

It is clear that if the UK is to provide the best care possible to young cancer patients, the NHS must take steps to improve support for those tasked with identifying cancer in children and young people. We have therefore made a series of practical recommendations for government and NHS decision makers that align with the existing policy context. CLIC Sargent looks forward to working with them to make tangible improvements to ensure that children and young people with cancer really do have the best chance from the start.

A handwritten signature in black ink that reads "Kate Lee".

Kate Lee
Chief Executive, CLIC Sargent

INTRODUCTION

Every year in the UK around 1,600 children aged 0 to 14 and 2,200 young people aged 15 to 24 are diagnosed with cancer (CRUK, 2015a; 2015b). Around 80% of children and young people with cancer survive. However, research tells us that the UK has poorer survival compared with some other European countries (Craft & Pritchard-Jones, 2007; CRUK, 2015a; 2015b).

Many children and young people with cancer experience a prolonged diagnosis, with one in four waiting more than three months for treatment (Ahrensberg et al., 2012). While it is well established for adults that delayed diagnosis has a negative impact, research has not been conducted to demonstrate the impact that a protracted diagnosis has on young cancer patients' chances of surviving their cancer (Lethaby et al., 2013; Neal, 2009).

However, previous research does tell us young cancer patients and their families can have negative experiences of the health system while seeking a diagnosis which have long-lasting implications for their trust in health care professionals and their ability to cope with their or their child's illness (Evans et al., 2015).

To better understand these issues we undertook research into the experiences of young cancer patients and parents of finding out that they or their child had cancer, with a particular focus on their experiences of primary care.

The key objectives of this research were to:

- Explore children and young people's routes to a diagnosis of cancer
- Understand young cancer patients' and parents' experiences of presenting symptoms to their GP
- Explore how experiences of care before diagnosis impact on children, young people and parents
- Identify the barriers to a swift and effective diagnosis according to GPs, other health care professionals, young people and parents
- Identify how best to support GPs to improve care prior to diagnosis for children and young people and their families
- Identify opportunities to improve care at diagnosis through national policy across the UK.

We hope that our research findings will add to the evidence base by providing further insight into the experiences of young cancer patients and their families in discovering they have cancer, and the difficulties GPs face when diagnosing cancer in this group. This information will help to indicate the support which GPs and other health care professionals need in order to identify suspected cancer in children and young people.

KEY FINDINGS

- Over half of young people (52%) and almost half of parents (49%) surveyed visited their GP at least three times before their cancer was diagnosed. A quarter of young people (24%) and one in five parents (18%) told us they required five visits or more to obtain a diagnosis
- A third of parents (34%) and just over half of young people (53%) reported that they felt their diagnosis was delayed. Of those, almost half felt that this perceived delay impacted on their prognosis. They also reported losing trust in their GP
- For young people and parents who reported a delayed diagnosis, the most common reasons cited were the GP misdiagnosing symptoms and having to visit the GP many times
- Nearly half of the young people surveyed (44%) said that they felt their GP did not take their concerns seriously
- Just over a third (34%) felt that their GP did not have time to listen to them talk about their symptoms. A quarter of parents (25%) felt that their GP did not have time to listen to them talk about their child's symptoms
- Two out of five parents (42%) reported that they felt their GP did not take their concerns seriously. A third (36%) thought that their GP did not take into account their knowledge of their child
- Nearly one in five parents (16%) felt that their child's ability to cope with their illness had been affected by their experience of the health system before diagnosis. Around the same proportion (14%) said that their own ability to cope had been affected. Just under a third of young people (31%) believed that their ability to cope with their illness had been affected by their experience of the health system
- Nearly half of UK GPs polled (46%) ranked lack of training available as one of their top three barriers to identifying cancer in children and young people
- When asked what additional support or advice would be beneficial in helping to identify the possible symptoms of cancer in children and young people, more than half of UK GPs polled (57%) said discussions about specific cases with experts, such as paediatric specialists, would help.

Context

Identifying suspected cancer in children and young people can be very difficult, given its rarity and often non-specific symptoms (Dommett et al., 2012; Evans et al., 2015). GPs are likely to see only one or two cases of childhood cancer in their career (Dixon-Woods et al., 2001).

According to the National Cancer Intelligence Network (NCIN) Routes to Diagnosis study, 53% of children aged 0 to 14 in England are diagnosed with cancer through emergency presentation, for example via Accident & Emergency (A&E) or an emergency referral (NCIN, 2015). This means they are more than twice as likely to be diagnosed through emergency presentation as young people aged 15 to 24, for whom 25% are diagnosed through emergency presentation, and older adults, who have emergency presentation rates of 20%.

This study went on to examine different pathways to emergency presentation for cancer patients. For all cancers combined, nearly 60% of emergency presentations were inpatient admissions following an A&E attendance and 30% were inpatient admissions following an emergency referral from a GP. The proportion of children with cancer aged 0 to 14 who were admitted following emergency presentations at A&E and those admitted after an emergency referral from a GP doesn't differ greatly from the rate for all cancer patients. One exception to this was sarcoma (cancer of the connective and soft tissue), which showed a noticeably lower proportion of GP emergencies (16%) and a higher proportion of outpatient emergencies (31%) (NCIN, 2013).

The impact of the disproportionate rate of emergency presentations on prognosis and outcomes for children has not been established. However, we do know that stress and anxiety caused by delay can have a profound effect. Parents and young people have reported feeling angry and frustrated, sometimes losing trust in medical professionals (Dixon-Woods et al., 2001; Gibson et al., 2013).

Research also demonstrates that poor communication with medical professionals, especially in primary care, is a problem. Young people and their families have reported not feeling listened to or taken seriously when they first presented their symptoms to their GP (Dixon-Woods et al., 2001; Evans et al., 2015; Gibson et al., 2013). Poor communication may therefore be a factor in prolonged diagnosis, as it can take repeated visits to the GP for action to be taken.

Not all children and young people have a negative experience of the health system before they are diagnosed, but in order to better understand the barriers to identifying cancer in young patients, we have chosen to focus on those who do. Our research explores the experiences of young cancer patients as well as those of parents, GPs and other healthcare professionals. Based on these findings we make recommendations for government and NHS action to improve support within the health system to identify suspected cancer in children and young people.

METHODOLOGY

This research aimed to explore children's, young people's and parents' experiences of finding out that they or their child had cancer, and their thoughts on how this impacted on them. Mixed methods were employed to ensure that opinions were gathered from a wide range of stakeholders.

Literature review

A literature review was undertaken to understand the existing evidence base. Studies on the experiences of young people and families prior to diagnosis were identified from a number of sources such as journal articles, other charitable organisations' reports, government reports and guidelines.

Online surveys

The literature review informed the design of two online surveys: one investigating the experiences of young people aged 16 to 24 who have or have had cancer, and one for parents of children who have or have had cancer. Multiple choice and free text questions were used. People's trust in their GP was also measured using the Revised Health Care Relationship Trust Scale (Bova et al., 2012). The surveys were piloted and developed by both young people and parents. A total of 147 young people and 186 parents responded. They were recruited from CLIC Sargent's networks, our care professionals and via social media. All percentages reported are drawn from the number of people who answered each question, not the total sample size. All figures from the surveys

are shown as a percentage and the actual number of respondents marked as 'n=' - for example 'Our survey found that around a third of young people (29%, n=27) had a diagnosis one to three months after first visiting a health care professional about symptoms.'

The survey respondents

Most of the young people who responded to our survey identified as female, some identified as male, and others did not identify their gender. Most said they were White British, and more than half told us they had finished active cancer treatment. The parents who responded to our survey reported that their child's age ranged from under one to 16 and over, of which more than two in five were still having active cancer treatment. Most of the parents who responded were female and White British.

Interviews

Telephone interviews were undertaken with four CLIC Sargent nurses, and seven CLIC Sargent social workers, to identify their views on how children, young people and their families find out they have cancer. Two parents of children with cancer were also interviewed. Interviews took place either face to face or via the telephone. The professionals interviewed included CLIC Sargent employed staff and CLIC Sargent funded staff, some of whom were NHS employees. Interviews were carried out by CLIC Sargent staff.

Focus groups

Three focus groups were conducted with young people to explore how they viewed their experience of finding out they had cancer. A total of 13 young people aged 15 to 25 took part, with each group having between four and five participants. Seven participants were female and six were male. All were White British. They came from different parts of the UK, including Scotland and Wales, and were recruited from CLIC Sargent's Children and Young People's Advisory Group. Most were not currently on treatment.

Poll of GPs

An online poll was commissioned to capture the views of GPs. This was carried out by ComRes on behalf of CLIC Sargent between 16 and 24 July 2015, with 1,002 GPs in the UK taking part. Quotas were set to ensure a representative spread of all GPs in the UK by former strategic health authorities, with all respondents verified by their General Medical Council

number. ComRes is a member of the British Polling Council and abides by its rules. Full data tables can be found at www.comres.co.uk.

Limitations of our research

Our surveys provide a snapshot of experiences. Participants were self-selecting and therefore are not necessarily representative of all children, young people with cancer and their families. However, given the rarity of cancer in children and young people we believe we have consulted with a significant proportion of this population.

The parents who volunteered to take part in interviews were sourced by CLIC Sargent professionals. The accounts of experiences prior to diagnosis were retrospective, so therefore are reliant on memory, and may be affected by subsequent experiences. It is possible that those with particularly negative experiences may have been more motivated to take part, in order to share their difficulties.



THE RESEARCH FINDINGS

ROUTES TO DIAGNOSIS

There is no one 'route to diagnosis' for children and young people with cancer. Each 0 to 24-year-old is different and has their own individual experience when they find out about their illness.

Some of our research participants reported interactions with a range of health care professionals when seeking a diagnosis, including optometrists, dentists, nurses, paediatricians and other specialists. However, in line with previous research, most parents and young people reported visiting their GP about their symptoms.

If a GP suspects cancer, they can make an urgent, very urgent or immediate referral to a specialist (BMJ, 2015).

"The first thing [the GP] did was made an immediate referral to the hospital. So there was no delay at that point. It was really good [...] then after that it was lots of examinations, assessments, CT scans, x-rays, I think he might have had one MRI."

(Parent of child with cancer)

While the process may work well for some, others reported a more complicated process, with parents sometimes seeking other routes to obtain a quicker diagnosis rather than waiting for a referral from their GP. Existing research has documented parents taking their child straight to A&E, using private or alternative medical professionals, consulting clinician friends or visiting specialists (Dixon-Woods et al., 2001).

Half of the parents who responded to our survey (50%, n=66) said that their first visit to hospital was via A&E. This was also the case for over a third of the young people who responded (38%, n=33). This may have been because they decided to visit A&E themselves, or it may be the result of a referral to A&E by their GP.

EXPERIENCES OF VISITING THE GP

Our surveys and interviews aimed to generate a deeper understanding of the experiences of young cancer patients and their families when seeking a diagnosis. While not all young people report that they visited a primary care setting as part of their journey to diagnosis, the majority of our respondents told us that they had visited their GP. This section reflects on those experiences.

Number of visits to the GP

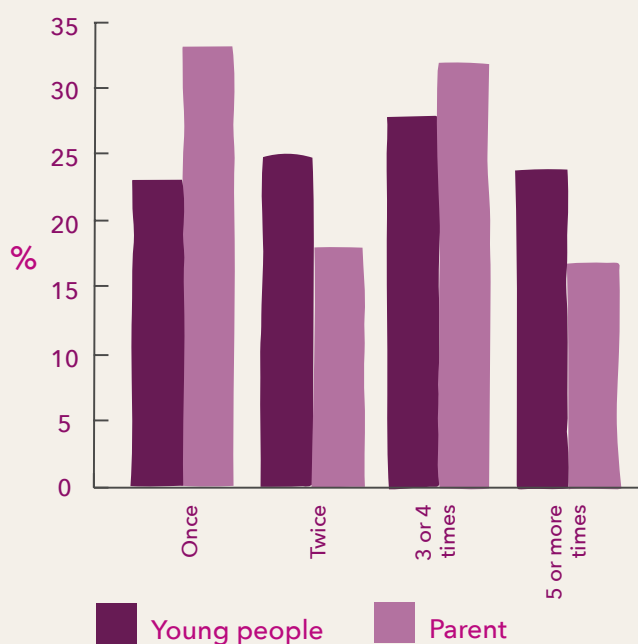
Research by Smith et al. (2007) discovered that 57% of young people with cancer surveyed visited their GP three or more times before they were referred to hospital. Of these, 29% visited their GP at least five times before they were referred.

Similarly, over half of the young people we surveyed (52%, n=46) reported visiting their GP at least three times, with a quarter (24%, n=21) visiting their GP five times or more before they were diagnosed. Almost half of the parents surveyed (49%, n=59) visited their GP at least three times about their child's

symptoms, with one in five (18%, n=22) seeing their GP five or more times before they were diagnosed.

Figure 1

How many times did you visit the GP?



Several visits to the GP may be required given the complexity of the cases. Nevertheless, our findings suggest that repeated GP visits can have negative consequences, which will be examined later in this report.

Time to diagnosis

Symptoms of cancers which affect children and young people can be vague and non-specific, and can resemble those of other childhood illnesses. GPs might not at first suspect cancer and may undertake tests to rule out other potential illnesses. When cancer symptoms are misinterpreted as those for other illnesses or viruses, diagnosis may be delayed or incorrect.

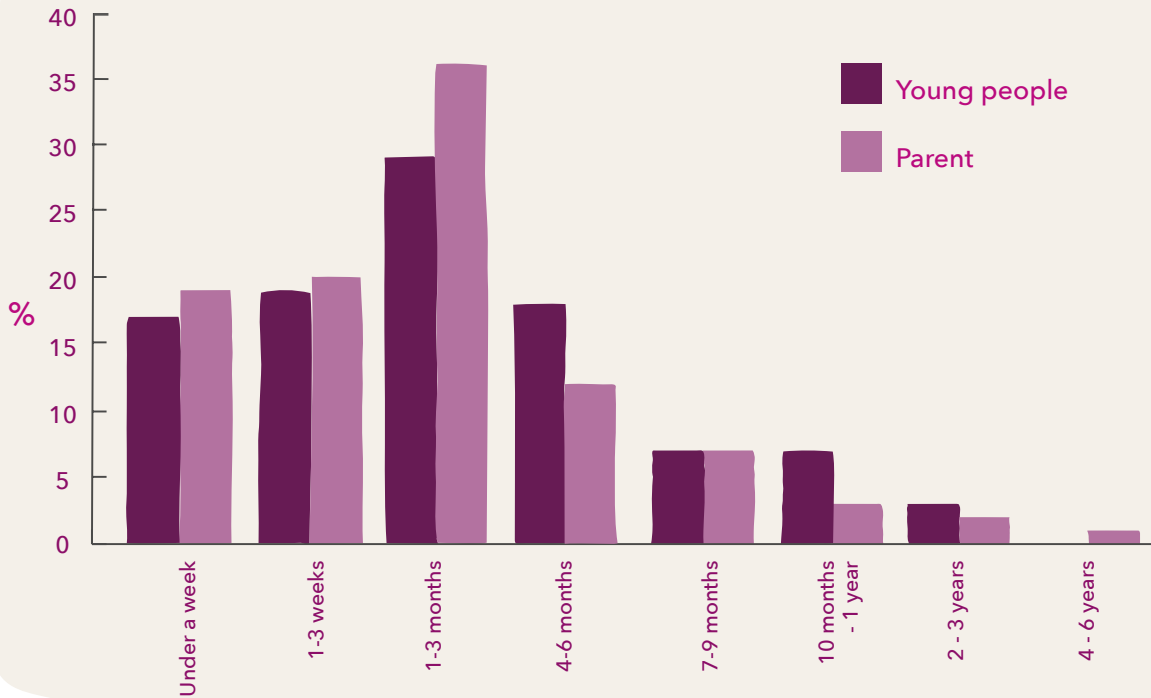
It is important to note that in our surveys, the notion of a delayed diagnosis was self-defining and therefore subjective. However, previous research has suggested that parent-reported diagnostic time and the diagnostic time recorded in medical records is similar (Evans et al., 2015).

Time to diagnosis for children and young people with cancer varies widely. One study in the UK found that almost a third were diagnosed within two weeks of visiting hospital and a third waited three weeks to eight months, but around 5% waited more than eight months (Smith et al., 2007). Additionally, a systematic review of diagnosis delays in childhood cancer found that the time to diagnosis ranged from 2.5 to 29.3 weeks (Dang-Tan & Franco, 2007).

Our surveys found that around a third of young people (29%, n= 27) and parents of children (36%, n=45) had a diagnosis one to three months after first visiting a health care professional about symptoms. However, over a third of young people (35%, n=33) and a quarter of parents (25%, n=31) reported that they waited longer than three months.

Figure 2

How long was it between seeing a health care professional and being diagnosed with cancer?



Reasons for delay

Many young cancer patients do not experience delays. Some young people and parents praised their GP for listening to their concerns and swiftly referring them.

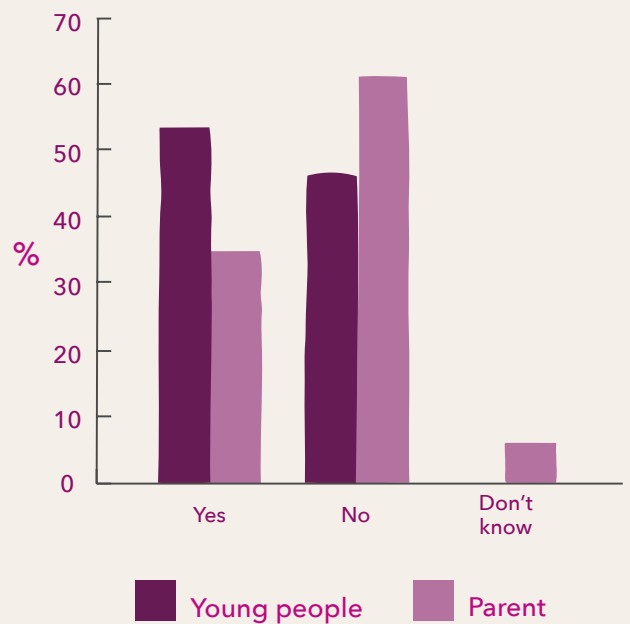
“There was two weeks between my surgery and my first symptoms, so it was really quick.”

(Young person with cancer)

However, while there may be a medical explanation for a lengthy period between initial presentation and diagnosis, of those responding to our surveys, a third of parents (34%, n=43) and just over half of young people (53%, n=43) reported that they felt their diagnosis was delayed.

Figure 3

Did you feel your diagnosis was delayed?



This is further supported by our interviews and focus groups. A significant number of the young people who spoke to us described a delay in their diagnosis.

"I first went to the GP about headaches when I was about 12 and I was diagnosed when I was 17." (Young person with cancer)

Where delay does occur, reasons previously documented include: inaction on the part of the GP; long waits for appointments, results and referrals; multiple visits to the GP and repeated misdiagnosis (Dixon-Woods et al., 2001; Gibson et al., 2013).

Our surveys uncovered a similar picture.

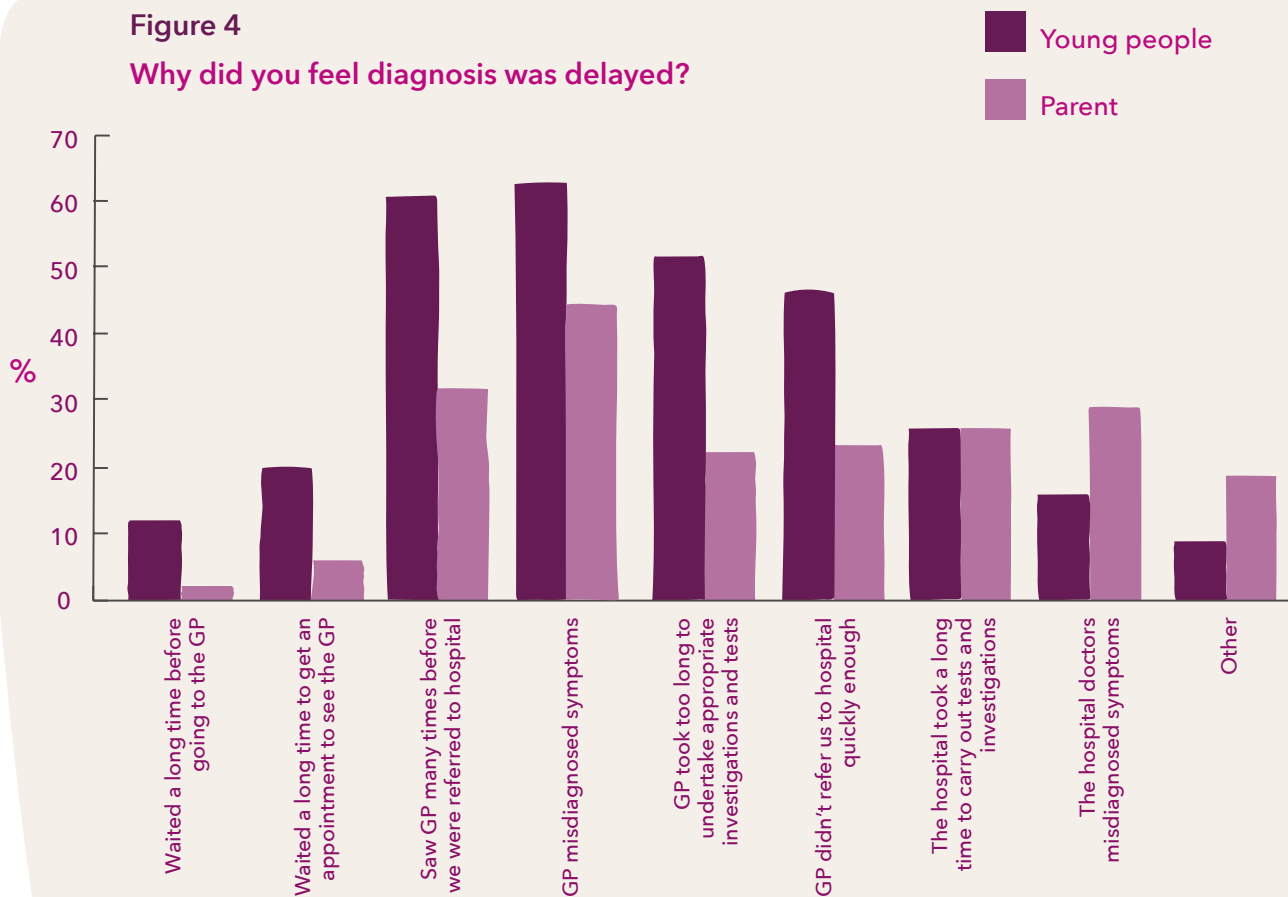
For the parents who reported a delayed diagnosis, the most common reasons they reported were:

- Misdiagnosis by GP (44%, n=19)
- Multiple GP visits (33%, n=14)
- Misdiagnosis by hospital (28%, n=12).

Among the young people who reported a delay, the most common reasons cited were:

- Misdiagnosis by GP (63%, n=27)
- Multiple GP visits (60%, n=26)
- GP took too long to undertake appropriate tests (51%, n=22)
- GP did not refer them to hospital quickly enough (47%, n=20).

Figure 4
Why did you feel diagnosis was delayed?



A number of the young people we spoke to told us that they felt that their delay was avoidable because their GP initially attributed their symptoms to growing pains and adolescence.

"[The GP] said you are going through puberty so you have headaches and occasional fainting and vomiting."
(Young person with cancer)

Several studies have found that young people are more likely to experience a delayed diagnosis than younger children. This is thought to be because of their increasing independence and subsequent reduced monitoring by parents and health services. It is also the case that younger children may present with more identifiable symptoms at onset than older children and there may also be a lower awareness of cancer symptoms in young people by both young people themselves and doctors (Dang-Tan & Franco, 2007; Haimi et al., 2011).

Tests

Delays can occur when waiting for tests and results to exclude other illnesses. CLIC Sargent health and social care professionals described how GPs often test young patients for other illnesses before cancer is diagnosed. Young people spoke about the 'trial and error' of testing for different illnesses. Sometimes young people and parents have a lengthy wait before receiving the results. Our interviews reveal that this can be a very stressful and frustrating time. Respondents emphasised that the delays can occur in hospitals and are not necessarily down to the GP.

"In October they did a biopsy, they took the lump away and sent it down to London to get it tested [...] everything went a bit quiet and then we got a phone call [10 weeks later] to say that he had cancer and that day they apologised for taking so long to tell us. [...] They had to test it several times and they said it's very rare. To me it wasn't good enough but I suppose I had to accept it." **(Parent of child with cancer)**

Primary care responses when health concerns are raised

Young cancer patients, and parents of a child with cancer, report a variety of experiences, both in terms of encounters with their GP and the GP's response.

One parent we interviewed told us that although their child's diagnosis took a long time to be made, they felt satisfied with the service that they received from their GP, whose decisions they trusted. Some young people also reported good communication with GPs. Our interviews highlighted that families and young people appreciate accurate, clear and digestible information from health professionals and that effective communication can instil confidence and build positive relationships.

"I think at the time I was satisfied with the service. [...] You trust their decision. They [GPs] did listen, they did listen to our concerns."
(Parent of child with cancer)

However, several studies have reported the experiences of parents who did not feel listened to or taken seriously by

their GP (Clarke & Fletcher, 2005; Dixon-Woods et al., 2001; Sloper, 1996), or who were spoken to insensitively (Levi et al., 2000). Others have described a fear of being perceived as 'neurotic' or 'overanxious' (Dixon-Woods et al., 2001; Sloper, 1996). Indeed, interviews with GPs have revealed that some are influenced by their preconceptions of parents as 'worriers' when making decisions in a consultation (Clarke et al., 2014).

Again, our surveys suggest that similar problems may persist. Two out of five parents (42%, n=49) felt their GP did not take their concerns seriously and over a third (36%, n=41) felt their GP did not take into account their knowledge of their child.

Parents have previously reported having arguments with the GP in order to obtain diagnostic tests (Clarke & Fletcher, 2005; Sloper, 1996). Reflecting on these challenges, interviewees told us how parents, in particular, sometimes feel that they have to fight to be listened to, resulting in feelings of anger.

"[A mother] also had to fight to get to be heard, and she pushed for scans, which they weren't going to give her... and this all took a lot of time and parents often blame the delay in making the diagnosis for how the child responds [...]" (CLIC Sargent Nurse)

Our interviews show that families' frustrations arise when they cannot see the steps professionals are taking to seek a diagnosis for unexplained symptoms or illness. This makes them

feel that their concerns are not being addressed. CLIC Sargent health and social care professionals told us that families often feel more listened to when they are at hospital when tests are being undertaken, or their child has received a diagnosis and is being cared for by specialists.

"I think they're more relieved that they're somewhere they're being listened to, all those symptoms have been taken seriously [...] Somebody's actually listened to them." (CLIC Sargent Nurse)

The CLIC Sargent nurses and social workers we interviewed felt strongly that parents are experts in their child's health and should be listened to carefully and taken seriously.

Young people with cancer can also feel that they are not listened to or taken seriously by their GP when first presenting to them with symptoms (Gibson et al., 2013). Zebrack et al. (2014) found that adolescents and young adults with cancer who were dissatisfied with their care cited poor communication with health care providers and delays in diagnosis as contributing factors.

Our survey of young people found that just over a third (34%, n=30) felt their GP did not have time to listen to them talk about their symptoms and nearly half (44% n=38) felt their GP did not take their concerns seriously. This perception was more prevalent among young people who were less satisfied with and had less trust in their GP.

The surveys found that young people were much more likely than parents to feel unable to talk to their GP and to feel they should not bother them with their symptoms. Communication problems between young people and doctors were discussed at the focus groups. Many of the views expressed reinforced the survey findings.

"I didn't feel like he [the GP] had really listened well the first time round, but then obviously people don't expect the worst."
(Young person with cancer)

"No-one would take me seriously."
(Young person with cancer)

Young people may find it especially difficult to communicate with GPs because they are less likely to have a parent present as an advocate and may have difficulty convincing doctors of the severity of their symptoms (Albritton & Eden, 2008). Additionally, health professionals may have less experience of talking to them as young people are less likely to present to their GP than other age groups (Tylee et al., 2007). Indeed doctors themselves have reported that communication can be problematic (Jacobson et al., 2001; McPherson, 2005).

THE IMPACT OF A DELAYED DIAGNOSIS

The impact of a delayed diagnosis of cancer in a child or young person on their prognosis, or their future health and psychosocial outcomes, is largely unknown due to lack of research and data analysis. Our research has sought to better understand young people's and parents' perspectives on the matter.

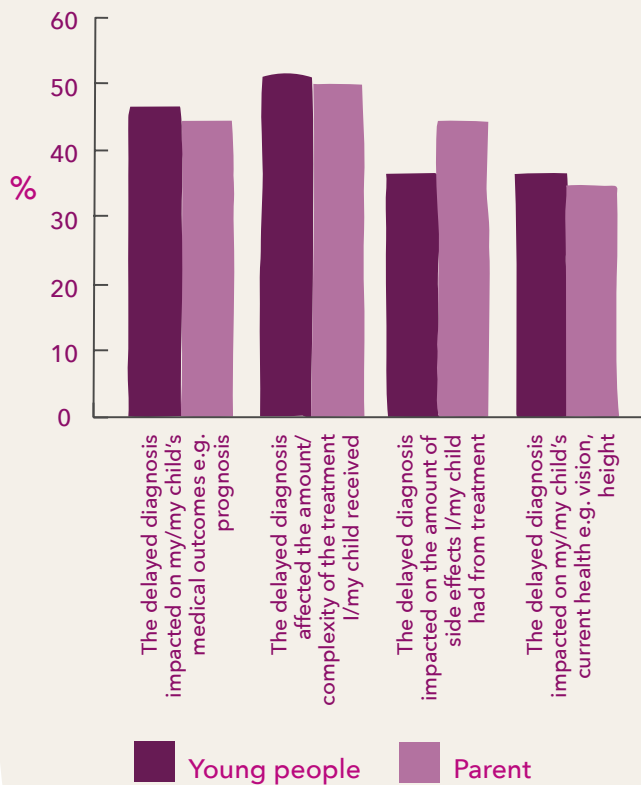
Impact on treatment and health

Poorer outcomes for adult cancer patients are associated with long diagnostic delays, but research on whether the same is true for children and young people is inconclusive (Brasme et al., 2012; Lethaby et al., 2013; Dang-Tan & Franco, 2007). A delay in diagnosis can also increase the amount or complexity of treatment, along with the chance of serious late effects (Evans et al., 2015; Lethaby et al., 2013).

Our research found that both parents and young people blamed their delayed diagnosis for their poorer outcomes. Of the parents who reported a delayed diagnosis, half (50%, n=20) felt that the complexity of their child's treatment was impacted by delay and nearly half (44%, n=18) felt that their child's medical outcomes were affected. Many also suggested that the delay had implications for their child's side-effects and on their current health. Around three in five parents (59%, n=24) felt that their child's delayed diagnosis had impacted on their own health.

Figure 5

What did you feel was the impact of a delayed diagnosis on your/ your child's health?



Just over half of the young people who reported a delayed diagnosis (51%, n=21) said that this had impacted on their treatment. Nearly half (46%, n=19) felt that their prognosis was impacted by the delay. The focus group participants who had experienced delayed diagnosis also suggested that this had had consequences. Some young people spoke about how they felt their tumours would have been smaller if recognised sooner and how being diagnosed with a later stage of cancer had impacted their physical health.

"I would have had a completely different life if they had diagnosed me earlier." (Young person with cancer)

Emotional impact

Research indicates that parents sometimes feel guilty for not seeking help earlier and for failing to identify symptoms or demand investigative tests for their child (Dixon-Woods et al., 2001; Evans et al., 2015). Our interviews produced the same finding.

Our surveys also found that a delayed diagnosis can have an adverse impact on the emotional health of both parents and young people. Just under two thirds of parents who reported a delayed diagnosis (63%, n=25) felt that it had impacted on the emotional wellbeing of their child. Most parents (81%, n=33) felt that the delay to their child's diagnosis had impacted on their own emotional health. Similarly, almost all of the young people who reported a delayed diagnosis (93%, n=38) said that their emotional health had been affected.

"At the time of initial diagnosis, there is anger, but their immediate priority is their child's health and how that child is going to be made better and how they are going to be supported through that journey." (CLIC Sargent Social Worker)

In addition, experiences before diagnosis can have an impact on the ability of young cancer patients and their parents to cope with the disease, which can have particularly serious implications for parents whose child dies (Dixon-Woods et al., 2001; Evans et al., 2015).

Nearly one in five parents we surveyed (16%, n=20) felt that their child's ability to cope had been affected by their

experience of the health system before diagnosis. Around the same proportion (14%, n=17) said that their own ability to cope had been affected. Just under a third of young people (31%, n=20) felt their ability to cope with their illness had been affected by their prior experience of the health system.

Impact on trust in GP

Parents and young people have reported feeling a lack of trust towards their GP after experiencing a delayed diagnosis (Brasme et al., 2012; Evans et al., 2015; Gibson et al., 2013; Teenage Cancer Trust, 2011). Nonetheless, our interviews reveal that parents and young people do understand the difficulties GPs face. They appreciate it when health professionals are willing to acknowledge mistakes.

“Sometimes the families just want somebody to say, ‘I’m sorry’ or ‘Sorry I didn’t listen to that part or what can I do better next time? How can I make it better for the next person?’” (CLIC Sargent Nurse)

Our surveys found that young people and parents have fairly high levels of trust in their GP, with parents reporting marginally more trust, as measured by the Revised Health Care Relationship Trust Scale (Bova et al., 2012). However, parents and young people who reported low levels of satisfaction with their GP were significantly less likely to trust them. Losing trust in the GP can have severe adverse psychological effects on patients and their families (Albritton & Eden, 2008). Our interviewees suggested that a poor journey to diagnosis can make it difficult for some families to move forward and rebuild trust once their child has been diagnosed.

“I’ve got no faith in [health professionals], I’ve got no faith in anybody really.”

(Parent of child with cancer)

“I really struggled to trust any other medical team, for you know...if I had been diagnosed at six, seven years old, when I should, I’d be fully sighted. My life would be completely different.”

(Young person with cancer)

However, previous research has found that even when parents felt disempowered in communicating with medical professionals, their trust was not necessarily lost forever (Sloper, 1996; Larsen et al., 2011). This is consistent with our interview findings: trust in the health system has the potential to be restored once treatment begins, if the family feels that their concerns are being addressed.

“You have these consultants who are very knowledgeable and that comes across. You know they’re very confident and determined in what they’re saying. And families actually like that. They feel a confidence from it.” (CLIC Sargent Social Worker)

THE CHALLENGES GPs FACE

GPs face a number of challenges in identifying suspected cancer in children and young people; including the rarity of the illness, limited training and awareness, time pressures and the nature of the referral pathway. We examined these issues in our UK-representative GP poll.

Cancer in children and young people is rare and difficult to diagnose

Government policy and practice guidance seeks to ensure health professionals are able to detect childhood cancer quickly (NICE, 2005). However, as has been discussed, this is not straightforward.

While severe symptoms such as seizures can be easier to identify, symptoms such as swollen glands, bruising, fatigue and weight loss can be easily misdiagnosed as other illnesses or issues such as viruses, sporting injuries, growing pains or stress (Albritton & Bleyer, 2003; Dixon-Woods et al., 2001; Smith et al., 2007).

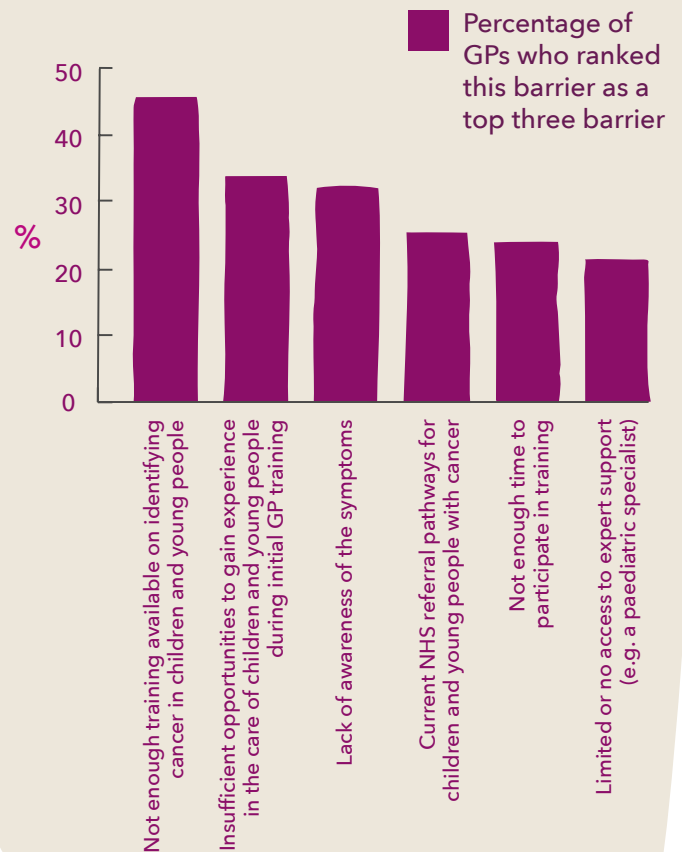
In our surveys, parents and young people reported that the most common symptoms of cancer were fatigue, pain, weight loss and lumps, but some said the illness was not obvious.

“I was never ill. [...] The only indication of anything that was wrong was my sight deteriorating.”
(Young person with cancer)

Nurses, social workers, parents and young people acknowledged the rarity of cancer in children and young people,

Figure 6

What are the barriers GPs face when identifying cancer in children and young people?



and the difficulties that GPs face in recognising its symptoms.

“I was told that the case of my cancer in a young person was probably the only case that my GP will ever see. Which is probably why they don’t jump to the conclusion when a young person comes in, they don’t think it is cancer, they think it is probably migraines or something.”
(Young person with cancer)

Almost a third of the GPs we polled (32%) said a lack of awareness of symptoms was one of the main barriers to identifying cancer in children and young people.

The need for GPs to rule out other illnesses experienced by children and young people first was also acknowledged by the young people and parents we spoke to. Interviewees recognised that this may take time, but that it may also cause frustration to parents or young people who do not feel the issue is being taken seriously enough.

When asked what additional support or advice would be beneficial in helping to identify the possible symptoms of cancer in children and young people, more than half of UK GPs polled (57%) said discussions about specific cases with experts, such as paediatric specialists, would help.

The Royal Colleges of Paediatrics and Child Health, General Practitioners and Nursing have published joint standards related to access to this expertise in *Facing the Future: Together for Child Health*.

These standards state that:

- GPs assessing or treating children with unscheduled care needs should have access to immediate telephone advice from a consultant paediatrician
- There should be a link consultant paediatrician for each local GP practice or group of GP practices.

It may be that action by clinical commissioning groups (CCGs) and GP practices to ensure that these standards are being implemented could help to ensure GPs access this support to discuss cases of suspected cancer in children and young people.

Training and experience in the care of children and young people

Previous research has shown that training and prior experience of hospital paediatrics is important when identifying children and young people who are seriously unwell (Clarke et al., 2014). A third (33%) of GPs said that insufficient opportunities to gain experience in the care of children and young people during their initial training was one of the top barriers to identifying cancer in children and young people.

Research has also identified that GPs need more information about young people's cancer, including the signs to look for (Gibson et al., 2013). Our GP poll found that nearly half of UK GPs (46%) ranked 'not enough training available on identifying cancer in children and young people' as one of their top three barriers to diagnosis. More than half (53%) said continuing professional development schemes on cancer in children and young people would be beneficial in providing them with additional support or advice on diagnosis. Just over half (51%) said more allotted time for training sessions to help them to better understand symptoms would help.

The majority of parents (79%, n=97) and young people (80%, n=65) that we surveyed agreed that GPs need more training. Findings from our young people's focus group also support this.

"It seems common that the GP maybe lacks knowledge [of cancer in children and young people]."
(Young person with cancer)

Our interviewees suggested that GPs with previous experience of diagnosing childhood cancer were quicker to accurately diagnose, but that they were in the minority. The CLIC Sargent nurses we interviewed considered it important for GPs to gain more exposure to specialist children's health services and that a stronger knowledge can be built through learning on the job rather than undertaking remote training.

"In my experience, the things that you see through working on the wards or working in the hospital is the stuff that you really remember. Your exposure to the clinical environment is a huge part of your education - and where you gain your knowledge." (CLIC Sargent Nurse)

Training can also improve GP communication skills with young people (McPherson, 2005) and parents, an important aspect of supporting children, young people and families at and beyond diagnosis.

Communicating with children and young people about cancer

Our GP poll found that a fifth of GPs in the UK (19%) would not feel confident about communicating with a child or young person who was describing the possible symptoms of cancer. Additionally, just under a quarter (23%) said they were not confident that they would understand the possible symptoms of cancer if they were described to them by a child or young person.

Two thirds of the young people (63%, n=50) and nearly half of the parents (44%, n=54) we surveyed agreed that GPs need more training in how to communicate with children and young people. Young people were significantly more likely to recommend this than parents, suggesting they may have specific communication concerns. This is worrying as young people who are unhappy with a consultation tend not to return, and those with cancer will almost certainly need to be monitored by their GP (Tylee et al., 2007).

Time pressures

The time pressures faced by GPs were identified by both interviewees and GPs themselves. Half of the GPs we surveyed (50%) said more consultation time to explore symptoms and identify cancer in children and young people would be beneficial. Indeed, GPs have previously reported that there is not enough time in a 10 minute consultation to properly examine a child and carry out appropriate investigations to identify cancer (Clark et al., 2014).

The majority of young people (79%, n=64) and parents (80%, n=99) agreed that GPs need more time to investigate symptoms in a consultation.

"GPs are so under pressure and I think you kind of feel like you're rushed and sometimes you probably forget to mention all the symptoms because you do slightly feel like they don't have enough time for you." (Young person with cancer)

CONCLUSION

CLIC Sargent undertook this research to better understand the experiences of children, young people and their families in seeking a diagnosis. The findings suggest that while a substantial proportion of young people and parents have positive experiences prior to receiving a diagnosis, a significant number do not. Many children, young people and parents visit their GP multiple times before receiving a diagnosis and many experience delays in obtaining a diagnosis. Furthermore, both parents and young people often feel that their GP does not have enough time to listen to them and does not take their concerns seriously.

For GPs themselves, a range of barriers exist that make identifying cancer in children and young people extremely difficult. These include the rarity of the

disease and the non-specific nature of its symptoms, which can easily be mistaken for common illnesses. Many GPs feel they do not have enough opportunities to be trained in how to identify cancer in children and young people. The time pressure under which they work can also impact on relationships and communication with patients and their families.

Poor experiences prior to diagnosis can have a profound effect on young people's and parents' trust in GPs, as well as on their emotional wellbeing. In the view of many parents and young people, it can also impact negatively on their medical outcomes. Good communication between GPs and parents and young people was cited as one of the key factors to improving experiences prior to diagnosis.



THE POLICY CONTEXT

In considering how the process of identifying cancer in children and young people can be better supported in the UK, it is useful to consider the current policy and practice context.

Improving cancer outcomes across the UK

In England, *Achieving world-class cancer outcomes: a Strategy for England 2015-2020* (Independent Cancer Taskforce, 2015) highlights the disproportionate number of children with cancer aged 0 to 14 who present through emergency routes. It also states the need for GP training and support, including from Clinical Commissioning Groups (CCGs), to make effective diagnoses and timely referrals.

In Northern Ireland, the *Cancer Services Framework* (Department of Health, Social Services and Public Safety, 2011) sets standards for cancer prevention, treatment and care. It is likely that policy on improving cancer outcomes will be updated following the Northern Ireland Assembly elections in 2016.

Better Cancer Care, An Action Plan (The Scottish Government, 2008) outlines how cancer services are required to support all those in Scotland who are living with and beyond cancer. The Scottish government is expected to publish a new cancer plan in early 2016, and the Managed Service Network for Children and Young People with Cancer will also publish a new strategy in 2016.

Together for Health, Cancer Delivery Plan for the NHS to 2016 (Welsh Government, 2012) sets the agenda for NHS Wales to work with its partners to tackle cancer.

In September 2015, an All Wales Cancer Conference brought together key stakeholders to consider priorities for Wales' next *Cancer Delivery Plan*.

Improving health outcomes for children and young people

Government and NHS leaders have not taken a similar strategic approach to improving the health of children and young people, as they have in improving cancer outcomes. However, policy documents and standards have been issued in each of the four nations.

In 2013, the Department of Health in England published the *Better health outcomes for children and young people* system wide pledge, which includes statements of shared ambition for improving children and young people's health services.

In Scotland the *Children and Young People (Scotland) Act 2014* places duties on public bodies to coordinate planning, design and delivery of services for children and young people, with a focus on wellbeing outcomes.

The National Service Framework for Children, Young People and Maternity Services (NHS Wales, 2005) sets standards for the quality of services that children, young people and their families have a right to expect and receive in Wales.

Northern Ireland has a 10-year strategy which covers the whole spectrum of policy issues related to children and young people entitled *Our Children and Young People - Our Pledge* (Office of the First Minister and Deputy First Minister, 2006).

Improving primary care

Looking at primary care in general, each of the UK's four nations has committed millions of pounds to making improvements for patients. These include greater access to GPs, including out-of-hours services, and major investment in GP recruitment, retention and training. In delivering these changes, there may be an opportunity to make improvements in the diagnosis of health conditions in children and young people such as cancer, if this is included as a specific policy aim.

Improving GP training

Although care of children and young people is a core component of the GP training programme, training in hospital-based paediatrics is not mandatory (Royal College of General Practitioners, 2010). As a result, fewer than half of GP trainees receive in-hospital paediatric experience (NHS Future Forum, 2012).

In January 2015, NHS England and Health Education England (HEE) launched *Building the Workforce – the New Deal for General Practice* which commits to recruit and retain GPs and support those returning to the workforce. HEE will work with partners to resource an additional flexible year of training to candidates seeking to work in areas where it is hard to recruit trainees, for example in paediatrics.

The Royal Colleges of General Practitioners, Nursing and Paediatrics and Child Health joint 2015 document *Facing the Future: Together for Child Health* standards also stresses the need for increased paediatric training for GPs,

rapid access to consultant paediatrician advice and better coordination between primary care and access to community children's nursing.

Guidance for GPs on recognising the signs of cancer in children and young people

Statutory guidance on the care and support to be delivered to children and young people with cancer acknowledges the difficulties that GPs face in recognising the symptoms of cancer in children and young people.

NICE guidance, *Improving Outcomes in Children and Young People with Cancer*, stresses the need for GPs to be equipped to make effective referrals and reduce the chance of a delay. This draws attention to additional NICE guidelines, *Suspected cancer: recognition and referral*, which were updated in 2015 and include a specific section on children and young people and this age group's different referral pathways. These guidelines recognise the need to listen to parents' concerns and for GPs to take into account parents' vital insight and knowledge when considering making a referral for suspected cancer, even when the symptoms may have a benign cause. It is anticipated that this will make it easier for GPs to refer patients for tests and help people receive a quicker diagnosis. It builds upon previous guidelines by bringing traditionally hospital-based tests under the wing of GPs. Importantly this includes screening tools for children and young people.

RECOMMENDATIONS

Future research

CLIC Sargent is concerned that gaps exist in the evidence base which have impeded service improvement in this area, and are likely to continue to prevent the UK from improving cancer outcomes for children and young people.

Further research is needed to understand how children and young people are diagnosed with cancer and the role primary care plays in this. Too little is known about GPs' experiences of recognising symptoms of cancer in children and young people. It is important to understand more about how GPs and children, young people and parents communicate, especially in circumstances where a diagnosis is not clear. In addition, more data are needed to explore the psychological consequences and prognostic implications of a delayed cancer diagnosis for children and young people.

Government and the NHS

This report highlights some of the current challenges for the health system in diagnosing cancer in children and young people. CLIC Sargent believes that high priority must be given to addressing these challenges, to ensure that children and young people with cancer do not face unavoidable delays or poor experiences.

Many of the issues raised in this report can only be solved with improvements to the evidence base, to NHS capacity to support primary care and to

professional practice. In order to achieve this, health ministers and NHS leaders, along with health system management and decision making bodies at a local level, must provide leadership and be accountable for improvements in outcomes for children and young people with cancer.

Recognising the policy context as well as the current evidence base, including our research, CLIC Sargent has created a series of recommendations for action. In creating these recommendations we have been informed by:

- *Facing the Future: Together for Child Health*, standards in primary care for children and young people published by the Royal Colleges of General Practitioners, Nursing and Paediatrics and Child Health; and
- *Achieving world class cancer outcomes: A Strategy for England 2015-2020*, which makes recommendations based on evidence submitted to an Independent Cancer Taskforce and includes insights which are applicable across the UK.

Tackling disproportionate rates of emergency admission

Recommendation 1: Health ministers should commit to publishing a statement of the impact that routes to diagnosis, in particular emergency admission after A&E attendance rather than GP referral, have on the survival rates of children with cancer aged 0 to 14 in each UK nation within the next two years, to address the current deficit in data analysis.

Recommendation 2: NHS leaders should create a requirement for a Significant Event Analysis (Independent Cancer Taskforce, 2015) to be undertaken when any child or young person is diagnosed with cancer as the result of an emergency presentation at A&E rather than a GP referral.

Improving initial and ongoing training in children and young people's health for primary care professionals

Recommendation 3: Health education bodies in each of the four UK nations should create a children and young people's primary care workforce development plan, which seeks to ensure that all GPs are offered greater opportunities to gain experience of children and young people's health during their initial training. This should be based on learning from initiatives such as those within *Building the Workforce - the new deal for General Practice* (Royal College of GPs, British Medical Association, NHS England, Health Education England, 2015), which offers extended training to GPs in hard to recruit to areas on topics such as child health.

Recommendation 4: Commissioners and providers in the health system should work with the voluntary sector and professional bodies to develop training programmes that provide continuing professional development opportunities for GPs and other primary care professionals in children and young people's cancer. They should also support access to education and knowledge exchange sessions with those who work with children and young people.

Promoting and incentivising good practice

Recommendation 5: Ministers and NHS leaders should ensure that medical professionals who come into contact with children and young people are required to demonstrate competence in listening, respecting and appropriately responding to concerns reported by children and young people, as well as their parents. Levels of competence should be monitored and evaluated, and best practice should be incentivised. Action should also be taken to understand and address workforce pressures that have an impact on primary care - for example, GPs, young cancer patients and parents shared their concerns in this report about the amount of time available for consultations.

Addressing system barriers

Recommendation 6: The NHS should evaluate the implementation of the new NICE referral guidelines to assess deliverability and impact by mid-2016. This should be differentiated by age bands to ensure that the guidelines are effective across all age groups.

Access to expertise

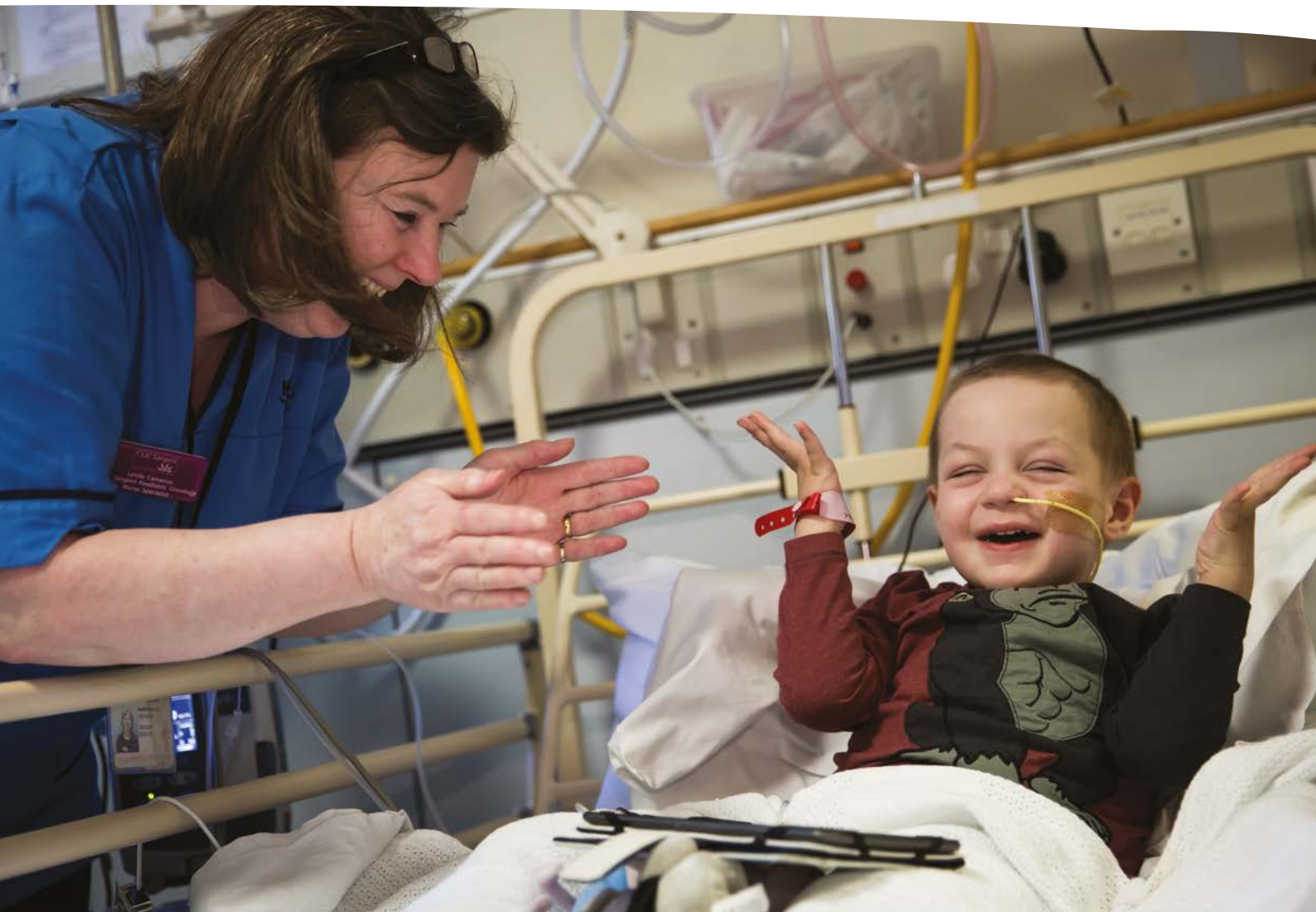
Recommendation 7: Each Health and Wellbeing Board should require their local Clinical Commissioning Group to report on the level of access that their GP practices have to paediatric and young people's health expertise - this should include information on action taken to address barriers to accessing this support. They should report against the following standards from *Facing the Future: Together for Child Health*:

- GPs assessing or treating children and young people with unscheduled care needs should have access to immediate telephone advice from a consultant paediatrician and an equivalent clinician with expertise in young people's health
- There should be a link consultant paediatrician and expert in young people's health for each local GP practice or group of GP practices.

Recommendation 8: Each Health and Wellbeing Board should work with Clinical Commissioning Groups in their area to ensure local GP practices are able to access specialist expertise, for example from experts in children or young people's health. They should identify and address any barriers that prevent GPs from accessing this support.

The role of CLIC Sargent

CLIC Sargent is committed to working with the government, policy makers, the NHS and professionals on the ground to help to address the issues raised in this report and to seek the implementation of our recommendations. We will also be calling on parliamentarians across the UK to help us to raise the profile of our concerns about the current barriers to identifying cancer in children and young people at a national level with the government and NHS, and at a local level with Clinical Commissioning Groups and Health and Wellbeing Boards.



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ACKNOWLEDGEMENTS

We would like to thank everyone who has helped us with the research including:

- All of the young people who responded to our survey and took part in our two focus groups
- All of the parents who responded to the survey and/or took part in an interview
- All the charities that helped to promote our survey on social media
- All of the CLIC Sargent health and social care professionals who shared their experiences in interviews
- All of the CLIC Sargent staff who helped to promote our surveys and arrange our interviews.



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