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Public awareness of childhood, teenager and young adult cancer signs and symptoms in Great Britain: a cross-sectional survey

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ABSTRACT

Objectives To assess public awareness of the risks and symptoms of cancer in children, teenagers, and young adults (CTYA) aged <18 years in Great Britain.

Methods A face-to-face computer-assisted opinion survey was conducted by Ipsos MORI. Participants were a population-based sample of 1000 adults (475 men, 525 women) aged >18 years, with 26% having children aged 6–15 in their households. Questions covered perception about cumulative cancer risk, confidence in recognising signs and symptoms, recognition and perceived urgency of classical signs and symptoms.

Results Only 32% of respondents felt confident in recognising CTYA cancer signs and symptoms. Symptoms deemed to require medical assessment within 48 hours by over 50% of participants included seizures/fits, blood in urine or stool, and persistent vomiting. All symptoms except one were selected for assessment within 3 months. On average, respondents identified 10.6 out of 42 classical signs and symptoms. The most recognised symptoms included lump, swelling in pelvis, testicle or breast (46%), blood in urine or stool (44%), changes to moles (43%), lump/swelling in the chest wall or armpits (41%) and weight loss (40%). The least recognised symptoms were early/late puberty (10%), developmental delay in children aged <2 years (11%) and slow growth (13%), with 8%, 2% and 6%, respectively, perceiving no need to discuss them with a doctor.

Conclusions Public awareness of childhood cancer risks and symptoms is substantially lower compared with adult cancer awareness in Great Britain. These findings indicate knowledge and awareness gaps among the general public, highlighting the need for a child cancer awareness campaign.

INTRODUCTION

Childhood cancer has been declared a global disease burden by the World Health Organization.¹ It is the leading cause of death in children over the age of 1 year and also a major cause of acquired disability linked to brain involvement and associated damage.² Five-year overall survival in Europe is approximately 81% in children and 87% in adolescents/young adults.³ In the UK, about 3755 new cases are diagnosed annually in children and young people under the age of 24 years.⁴ Survival rates have been reported to lag behind those in the rest of Europe.⁵ Evidence in Wilms' tumours also shows

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Children and young people (0–18 years) present with non-specific symptoms mimicking other more common ailments.
- ⇒ Public awareness of adult cancer symptoms is high, but there is a paucity of research/large-scale survey on public perception of childhood cancer risk, signs and symptoms.

WHAT THIS STUDY ADDS

- ⇒ Perceived rarity of cancer in children is one of the key barriers in permitting early diagnosis. This needs to be communicated with the public and all healthcare professionals involved in the diagnostic pathway.
- ⇒ Symptom awareness is substantially lower than for adult cancers, in particular slow growth or early or late puberty, slow recovery from skeletal injuries in children and young people, abnormal eye movements and leukocoria in babies and infants.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The findings identify gaps in public awareness of cancer in children and young people. Building on this awareness and enhancing serious symptom awareness for children and young people is a key priority.
- ⇒ These findings highlight a need for targeted activities to address disparities in childhood cancer symptom awareness among different demographic groups.

that UK children present with a larger tumour and at a more advanced stage at diagnosis compared with Germany.⁶ Recent data from 2012 to 2016 showed that 5-year survival has improved to 85% although, for certain tumour types, survival remains poor.⁷ There are many reasons why survival varies by country and tumour type, and delayed diagnosis may be playing a key role.

Cancer in children and young people is a multifaceted problem as symptoms usually mimic more common ailments. The wide range of clinical presentations can be applied to the differential diagnosis of almost any clinical presentation.⁸ Practitioners wait for evidence of symptom persistence



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or progression to evolving symptom clusters before initiating further investigations, not all of which can be organised from primary care for children in the UK. This approach delivers life-threatening and disabling presentations at diagnosis due to characteristically rapidly advancing disease. A survey revealed that 53% of young people and 34% of parents perceived a delay in their cancer diagnosis, with 50% having visited their GP at least three times before diagnosis.⁹ Given that childhood cancers are not preventable and screening tests are currently unavailable, public and professional symptom awareness methods promoting early diagnosis are the favoured way to close the gap and improve the outcome.

Accessing services for timely diagnoses has been high on the government agenda due to the clear clinical need, with a focus on adult cancers^{10–12} but not children.¹³ Public awareness campaigns have proven successful in educating the public about red flag symptoms in adult cancers and accelerating diagnosis with improved outcomes.¹⁴ For children and young people, population campaigns have focused on brain tumours, testicular cancers and retinoblastoma,^{15–17} and no national government-funded campaigns for childhood cancers have been launched.

Child Cancer Smart (<https://www.cclg.org.uk/childcancersmart>) is a UK public and professional awareness campaign aiming to raise awareness of the symptoms and signs of all children, teenagers and young adult (CTYA) cancers. The aim of this project is to assess the level of knowledge and awareness on the symptomatology of childhood cancer among the general public.

METHODS

The Children's Cancer and Leukaemia Group (CCLG) instructed Ipsos MORI to conduct a cross-sectional opinion survey in May 2019 using face-to-face computer-assisted interviews with a population-representative sample of 1000.

Data collection

Demographic data including age, sex, ethnicity, government office region, social grade based on the occupation of the chief

income earner,¹⁸ highest qualification and whether they have children under the age of 16 in the household were collected. The questionnaire consisted of six questions, including prompted awareness of signs and symptoms using a show card (table 1). Signs and symptoms were grouped by body part/system and respondent's intuition/concern (see online supplemental table S1). Participating in the survey was voluntary and offered a 'prefer not to say' option if the respondents did not wish to answer the question.

Statistical analysis

Results were weighted to be representative of the Great Britain population. Descriptive statistics, χ^2 test, t-test or analysis of variances (ANOVA) were used to compare the differences between subgroups. Bonferroni correction was used for multiple comparisons where appropriate. ORs and 95% CIs were estimated using logistic regression. Data analysis was carried out using SPSS Version 27.0 (IBM Corp, Armonk, New York, USA). P values <0.05 were considered statistically significant in all analyses.

RESULTS

Study population

The population-based sample consisted of 1000 respondents over the age of 18 (weighted n=993, online supplemental table S2). Approximately 48% were men, 87% were white, 9% from Scotland and 5% from Wales, 13% were young people aged 18–24 years, and 32% had children aged <16 years in the household.

Perception of public about cumulative childhood cancer risk to age 15 years

About 49% of the respondents, 51% of young people aged 18–24 and 51% of those with children under 16 in the household reported this risk was higher than they expected. Subanalyses showed no significant difference by age group, ethnicity, country, social grade or the presence of children

Table 1 Survey outcome measures and questions

Key measures	Question
Perception of public about cumulative childhood cancer risk to age 15 years (<i>informed that it is 1 in 450</i>)	About 1 in 450 children will be diagnosed with cancer by the age of 15. Is that... (5-point Likert scale: 1=a lot more than expected to 5=a lot less than expected)?
Perception of public about cumulative childhood cancer risk to 25 years (<i>informed that it is 1 in 180</i>)	About 1 in 180 children, teenagers and young adults will be diagnosed with cancer by the age of 25. Is that... (5-point Likert scale: 1=a lot more than expected to 5=a lot less than expected)?
Percentage of public that are confident in recognising childhood cancer signs and symptoms	How confident or not are you that you personally would be able to identify signs and symptoms of cancer in children and young people under the age of 18? (Very confident, fairly confident, not very confident, not at all confident)
Sources of health information/advice	If you need to, which, if any, of the following things would you do to look for further information and advice on signs or symptoms of cancer in children or young people under the age of 18? <ul style="list-style-type: none"> ► Consult the GP ► Ring NHS telephone helpline (NHS Direct or 111) ► Speak to a family member or friend ► Look on NHS website (NHS Direct or NHS A to Z) ► Speak to the local chemist or pharmacist ► Consult a health visitor ► Internet search (eg, Google) ► Consult a medical specialist ► Speak to the school nurse ► Research it at the library ► Something else ► I would not seek further information or advice for a child or young person
Length of time before public discuss signs/symptoms with a doctor (prompted with a symptom list)	Which, if any, symptoms do you think need discussing with a doctor within 48 hours, within 2 weeks, within 3 months and also the symptoms that do not need to be discussed with a doctor at all?
Percentage of public that were aware of childhood cancer signs/symptoms (prompted with a symptom list)	Which of the following would you consider as a symptom of cancer in children and young people under the age of 18?

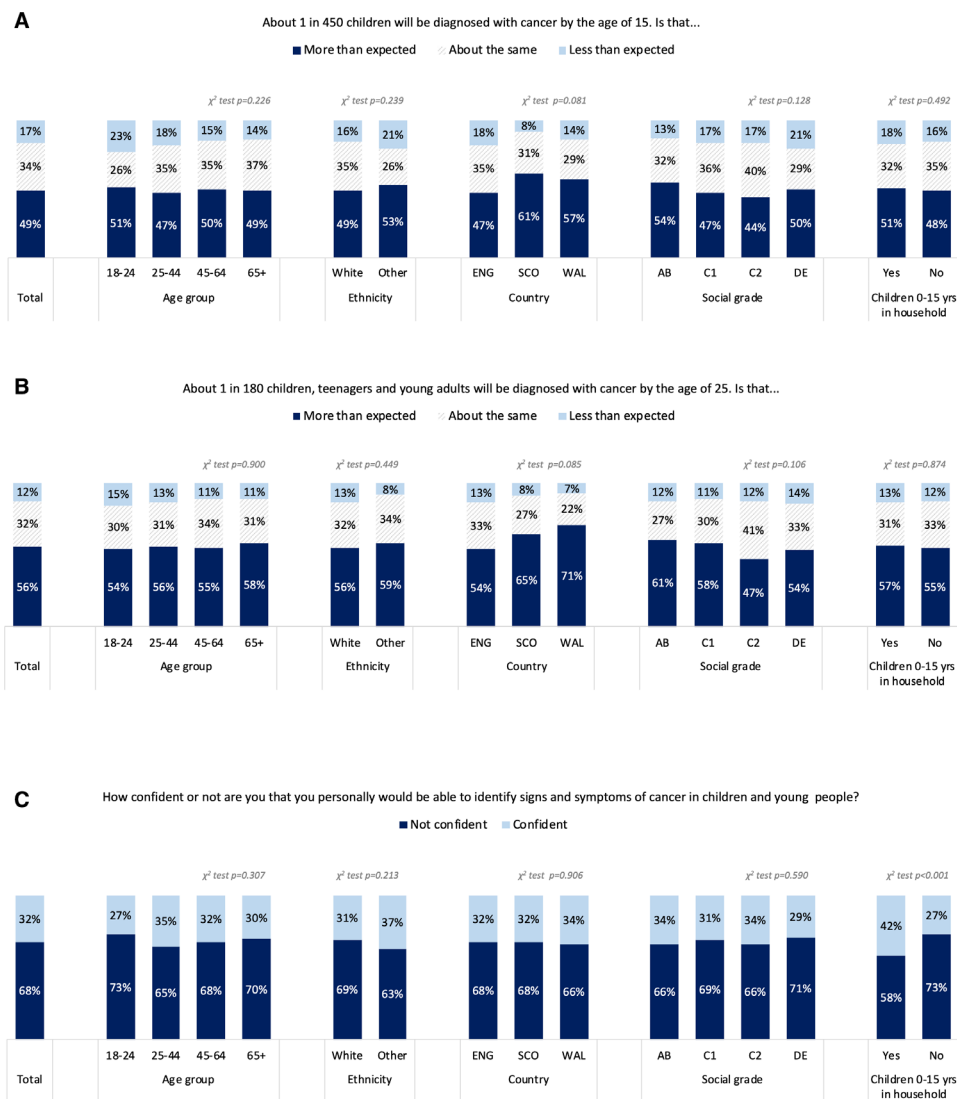


Figure 1 Public perception of cumulative cancer risk and self-reported confidence in recognising signs and symptoms of childhood cancer. (A) Perception of public about cumulative childhood cancer risk to age 15 years. (B) Perception of public about cumulative childhood cancer risk to age 25 years. (C) Percentage of public that are confident in recognising childhood cancer signs and symptoms. Respondents who answered 'don't know' were excluded from the analysis. Total number may not add up to 993. For full data see online supplemental table S3.

aged 0–15 years in the household (see figure 1A, online supplemental table S3).

Perception of public about cumulative childhood cancer risk to age 25 years

Approximately 56% of the respondents, 55% of young people aged 18–24 and 57% of those with children aged <16 years in the household felt the risk was higher than expected. There was no significant difference in distribution by age group, ethnicity, country, social grade or the presence of children aged 0–15 years in the household (see figure 1B, online supplemental table S3).

Confidence in identifying signs/symptoms

Sixty-eight percent of respondents lacked confidence in identifying signs and symptoms of childhood cancer (see figure 1C, online supplemental table S3). Confidence was similar across age groups, ethnicity, country and social grade, but higher in respondents with children aged <16 years in the household (42%) compared with those without

(27%, $p<0.001$). Including 'don't know' responses did not change the pattern (data not shown).

Source of health information

Respondents mentioned an average of 2.7 out of 10 pre-coded sources. The top five sources were GP (71%), NHS website (35%), internet search (34%), medical specialist (31%) and NHS telephone helpline (27%, figure 2).

Although common sources were the same, the patterns varied across subgroups. In England, GP was mentioned by 69% of the respondents, which was significantly lower than in Scotland (87%, $p=0.002$). The NHS website ranked second in white respondents but fourth among ethnic minorities (37% vs 24%, $p=0.006$). Similarly, NHS website and internet search were more commonly mentioned by social grades AB/C1 (38–48%) than C2/DE (24–26%). Family and friends were mentioned by 27% of the respondents aged between 18–24, the highest across all age groups. It was also more commonly mentioned by white respondents than others (19% vs 11%, $p=0.025$).

If you need to, which, if any, of the following things would you do to look for further information and advice on signs or symptoms of cancer in children or young people under the age of 18?

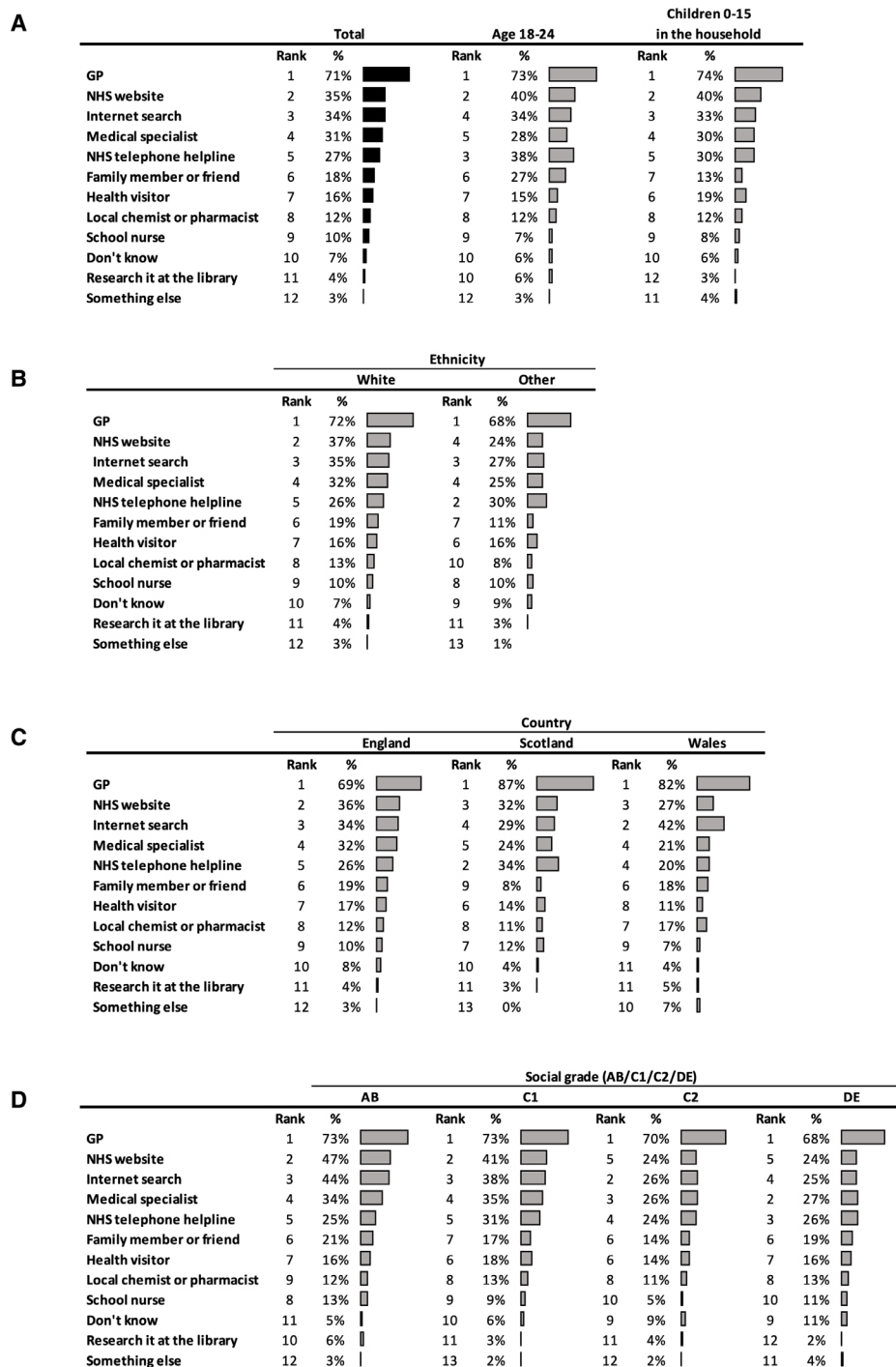


Figure 2 Source of health information on signs or symptoms of CTYA cancer under the age of 18 years in (A) general public, young people aged 18–24 years and those who have children aged 0–15 years in their household; (B) by ethnicity; (C) by country; (D) by social grade (AB, higher and intermediate managerial, administrative, professional occupations; C1, supervisory, clerical and junior managerial, administrative, professional occupations; C2, skilled manual occupations; DE, semi-skilled and unskilled manual occupations, unemployed and lowest grade occupations).

Length of time before seeking medical advice

The top five symptoms that respondents felt needed to be discussed with a healthcare professional if no improvement occurred within 48 hours were: seizures or fits (62%), blood in urine/stool (57%), persistent vomiting (50%), lump/swelling in pelvis, testicle or breast (49%), excessive bleeding, bruising, rash or petechiae (49%). Less urgent symptoms for which

respondents would allow more than 3 months to pass or not seek medical advice were early/delayed puberty (55%), slow growth (48%), developmental delay in young children aged <2 years (46%), persistent/recurrent sore throat or hoarse voice (43%) and slow recovery after bone or joint injury (43%). Notably, slow growth and early/delayed puberty were not considered as symptoms to discuss with doctors by 6% and 8%

Which, if any, symptoms you think need discussing with a doctor within 48 hours, within 2 weeks, within 3 months and also the symptoms that do not need to be discussed with a doctor at all.

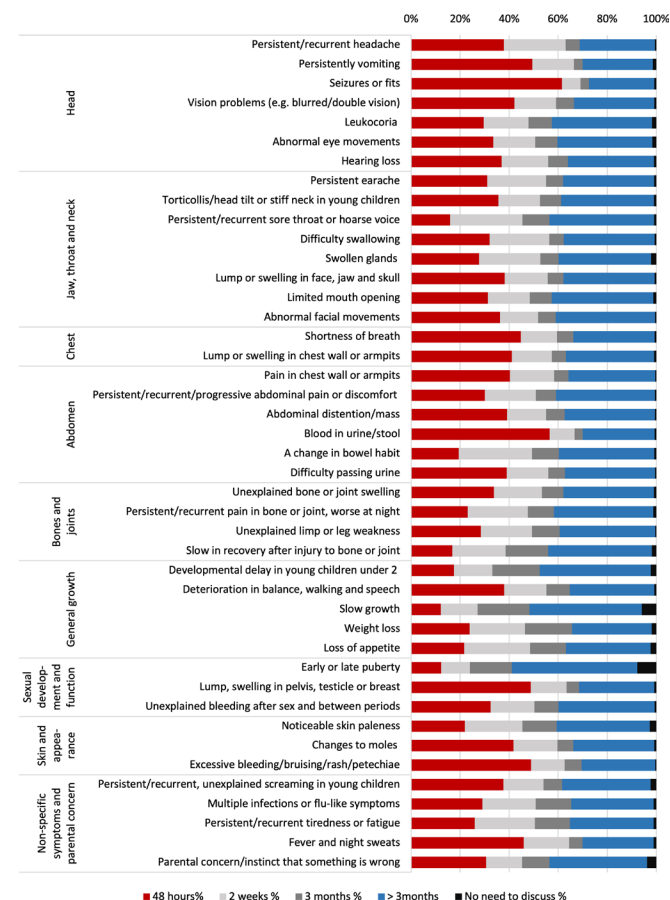


Figure 3 Length of time before public would make an appointment to discuss high-risk symptoms with a doctor. Red bars represent the proportion of respondents who think the symptom needs to be discussed with a healthcare professional within 48 hours if there is no improvement and blue bars represent the proportion of participants who think the symptom would need to be discussed with healthcare professionals if there is no improvement after 3 months. For full list see online supplemental table S4.

of respondents, respectively (see [figure 3A](#), online supplemental table S4).

Recognition of signs/symptoms

The most recognised symptoms were lump or swelling in pelvis, testicle or breast (46%), blood in urine or stool (44%), changes to moles (43%), lump or swelling in chest wall or armpits (41%) and weight loss (40%, [figure 4](#)).

Awareness was low for growth and developmental symptoms such as early/delayed puberty (10%), developmental delay in children aged <2 years (11%), slow growth (13%), slow recovery after bone or joint injury (14%) and leukocoria (18%, [Figure 4](#)). Prompted awareness of these symptoms by demographic factors is shown in online supplemental table S6.

Factors associated with low symptom awareness

The average number of symptoms mentioned was 10.6 out of 42, significantly lower in ethnic minorities and those from social grades C2 and DE (see online supplemental table S5). The difference between white and ethnic minorities was only significant in

Which of the following would you consider as a symptom of cancer in children and young people under the age of 18?

Signs and symptoms	All respondents	Aged 18-24	Children aged 0-15 in household
	%	%	%
Lump, swelling in pelvis, testicle or breast	46%	46%	46%
Blood in urine or stool	44%	39%	45%
Changes to moles	43%	36%	42%
Lump or swelling in chest wall or armpits	41%	38%	41%
Weight loss	40%	34%	44%
Abdominal distention/mass	38%	35%	36%
Lump or swelling in face, jaw and skull	36%	36%	34%
Persistent/recurrent headache	32%	32%	34%
Persistent/recurrent tiredness or fatigue	32%	26%	34%
Loss of appetite	31%	26%	34%
Persistently vomiting	31%	33%	29%
Excessive bleeding/bruising/rash/retchiae	30%	24%	28%
Seizures or fits	29%	26%	27%
Pain in chest wall or armpits	29%	26%	28%
Unexplained bone or joint swelling	27%	23%	26%
A change in bowel habit - constipation or diarrhoea	27%	18%	26%
Persistent/recurrent/progressive abdominal pain or discomfort	26%	21%	28%
Difficulty passing urine	26%	19%	27%
Vision problems (e.g., blurred or double vision)	26%	24%	25%
Swollen glands (side of the neck)	26%	24%	26%
Deterioration in balance, walking and speech	23%	21%	21%
Persistent/recurrent pain in bone or joint, worse at night	23%	18%	23%
Noticeable skin paleness	22%	23%	24%
Multiple infections or flu-like symptoms	22%	21%	22%
Unexplained bleeding after sex and between periods	22%	16%	24%
Fever and night sweats	21%	22%	24%
Shortness of breath	21%	20%	25%
Difficulty swallowing	21%	16%	20%
Unexplained limp or leg weakness	20%	21%	19%
Parental concern/instinct that something is wrong	20%	16%	22%
Don't know	19%	21%	17%
Persistent/recurrent, unexplained screaming in young children	19%	14%	19%
Persistent/recurrent sore throat or hoarse voice	18%	11%	18%
Torticollis/head tilt or stiff neck in young children	18%	14%	19%
Leukocoria	18%	13%	17%
Hearing loss	17%	16%	16%
Abnormal eye movements	17%	14%	17%
Abnormal facial movements	16%	11%	16%
Persistent earache	16%	12%	14%
Limited mouth opening	14%	10%	13%
Slow in recovery after injury to bone or joint	14%	13%	15%
Slow growth	13%	10%	15%
Developmental delay in young children under 2	11%	12%	12%
Early or late puberty	10%	8%	11%

Figure 4 Prompted awareness of signs and symptoms of childhood cancer. The colour red indicates low awareness of childhood cancer signs and symptoms and the colour green represents higher awareness with percentages ranging up to 50%.

social grades C1, C2 and DE, suggesting a potential interaction (see online supplemental figure S1).

In the absence of an agreed definition, the group median of five symptoms was used as the cut-off for low awareness (see online supplemental table S5). Ethnic minorities were more likely to have low awareness (OR 3.6, 95% CI 2.34 to 5.54). Similarly, people in social grades C1/C2/DE showed higher likelihood of lower awareness than those in social grade AB (ORs 1.54, 2.78 and 2.66, respectively).

DISCUSSION

The survey findings show that the public is unaware of childhood cancer risk, has a lack of confidence in recognising signs and symptoms, and has low knowledge of CTYA cancer symptoms. The results also highlight lower symptom awareness in ethnic minorities and participants from less affluent backgrounds. Targeted awareness activities will be necessary to bridge these gaps.

Perceived rarity of cancer in children is a key barrier to early diagnosis. While the number of cases may be small compared with adult cancers, the cumulative risk from birth to early adulthood is comparable to that of other childhood illnesses.⁸ This needs to be communicated with the public, as parents usually associate common symptoms with common childhood ailments but not cancer.

Common sources of health information were, as expected, primary care as a first port of call and the NHS website as the next popular option. This again re-confirmed the essential roles of all healthcare professionals in early diagnosis. Oncological vigilance in childhood is necessary for both the general public and healthcare professionals caring for children and young people.

Symptom awareness

Childhood cancer symptom awareness in the survey ranged from 10% to 46%, which was significantly lower than that in an adult awareness survey (63–94%).¹⁹ The most recognised symptoms also coincide with the red flag symptoms highlighted in adult cancer awareness campaigns.¹⁰

This pattern has previously been reported in surveys using modified Cancer Research UK cancer awareness measure questionnaires to assess cancer awareness among adolescents.^{20–22} In England, 68% of adolescents aged 11–14 years did not know the most common CTYA cancers, citing breast or lung as the most common, and one-third could not list any cancer symptoms.²² Another study surveying 478 students aged 11–17 years found half the respondents did not know the most common CTYA cancers and 69% believed cancer was unrelated to age.²¹ Furthermore, symptoms with high levels of recall and recognition were all symptoms of adult campaigns such as lump/swelling, change of bowel/bladder habits, hair loss, pain or fatigue and change in appearance of moles.^{20–22} This suggests that knowledge is currently driven by adult symptom awareness campaigns, posing a challenge in childhood cancer awareness. Enhancing serious symptom awareness for children and young people is a priority in our campaign.

Our survey respondents failed to recognise that a growth problem or early/delayed puberty could indicate ill health. Slow recovery after bone/joint injury and leukocoria, which are classic symptoms of bone tumours and retinoblastoma, was also poorly recognised. Respondents' estimate of safe intervals before seeking medical advice were measured in weeks and months for most symptoms. Knowledge on how long sports injury would improve/recover and when to seek further medical advice is also poor.

Slow growth or early or late puberty should be assessed by a paediatrician. Persistent skeletal injuries in children and young people beyond 2 weeks require further evaluation. Abnormal eye movements and white pupils in babies and infants require an optician or ophthalmologist review. These are crucial behaviours for change and key messages to communicate through this public awareness campaign.

Strengths and limitations

In searching the literature, a lack of understanding was noted regarding public awareness of childhood cancer symptoms in comparable countries and a scarcity of validated awareness questionnaires for CTYA cancers. Our questionnaire design and the use of a symptom card was largely based on experience from the HeadSmart paediatric brain tumour awareness campaign.²³ We opted for a longer, more sophisticated symptom list stratified by body part/system rather than age group. This would allow us to prioritise the areas/symptoms to communicate with target audiences and develop educational materials for healthcare professionals in different specialties. The symptom list has also been employed in a UK observational study to describe referral pathways and diagnostic intervals in children and young people with

cancer,²⁴ which will provide the opportunity for direct comparisons in the future.

This survey targeted the general public as we believe that all adults should be aware of childhood cancer signs and symptoms, since 88% of the adults have regular contact with children and young people either through their profession or as family members.²³ Their perception and behaviour significantly impact potential patient delay in children.

One limitation of the survey is the under-representation of adolescents, especially those aged 16–18 years. Conducting a regional/national survey among adolescents on a potentially worrying topic like cancer requires a different approach, often involving school-based surveys with ethical safeguards and parental consent.^{20–22} Even in that setting, those who are not in full-time education will still not be captured. The awareness and help-seeking behaviour in this population therefore needs to be assessed separately.

A show card/multiple choice approach meant that respondents could give answers without any prior knowledge. Comparing the results with unprompted open questions would be ideal but, due to the availability of resources, recall of symptoms will only be carried out in healthcare professional awareness surveys.

Potential bias

The survey questionnaire was carefully structured. The question order was arranged to avoid revealing the cancer theme at the beginning of the survey. We also produced two show cards, one in forward and the other in reverse order, to mitigate potential bias.

Despite our best efforts, we cannot rule out the possibility of response bias, where respondents provided answers that deviate from their true perceptions. Some respondents might be inclined to give socially desirable answers, select all positive/negative or all extreme/neutral options. The impact of response bias on the survey can lead to either over- or underestimation of the true awareness or relationships. Therefore, it is essential to interpret the survey results carefully, viewing them as indications of patterns, trends or gaps in knowledge while keeping these limitations in mind and avoiding over-interpretation.

Childhood cancer awareness campaign

Awareness has been marked as a key strategy for early cancer diagnosis in the UK,²⁵ but there has been little focus on childhood cancers. Accelerating CTYA cancer diagnosis enables identification of cancers at lower stages and also prevents further lifelong disabilities. This potentially provides greater health economic savings for the families and NHS than those identified for the more common adult cancers once their quality-adjusted life years in early life are taken into account. The Child Cancer Smart national awareness campaign will promote early diagnosis through high-quality evidence-based guidance and awareness tools for both the public and healthcare professionals.

CONCLUSIONS

The survey identified that awareness of the risks and signs and symptoms of childhood cancer are substantially lower than awareness for the adult cancer population in Great Britain. These gaps of knowledge have permitted us to identify key learning points for the evolving Child Cancer Smart campaign. We are currently assembling a UK database of cancer referral pathways in children and young people to further inform the campaign. We are using multiple social marketing channels with simple evidence-based and age-stratified messages to raise both

public and professional awareness with the intention of shortening the time to diagnosis.

Twitter Dhurgsharna Shanmugavadivel @HeadSmartFellow and Ashley Ball-Gamble @ashleysgamble

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