2020 PATIENT SURVEY

An in-depth analysis on the signs, symptoms, and routes to diagnosis for primary bone cancers and tumours.

BONE CANCER RESEARCH TRUST
UNTIL THERE'S A CURE

Why is early diagnosis important to our patients?

Had this lump been X-rayed sooner, she would have been in the early stages and also further into treatment. I would love and hope for sarcoma to be considered at every triage a patient has who comes in with an unexplained lump or mass in any bony area.

Harmony's Dad, Aaron

Early diagnosis is of paramount importance. The 23 appointments Alice had before diagnosis were with GPs, physios, A&E doctors and even a consultant orthopaedic surgeon who specialises in hip and knee surgery. All of them missed where the 7cm-9cm tumour was and none of the medical staff along our pre-diagnosis journey suspected Alice's symptoms could be bone cancer. Alice's dad, Nick

Awareness is so important. If caught earlier, it may not have spread to her neck and she may not have lost as much of her pelvis. As it stands, she could also still end up with secondary cancer from the treatment she has received with it being so aggressive.

Abigail's mum, Ellie

I think the more awareness we can raise about early diagnosis, the better the treatment outcomes will be. Just one mention of this at a GP visit could make such a difference.

Sophie

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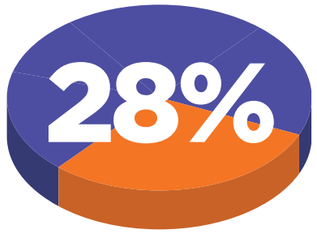
About primary bone cancer

Primary bone cancer is a rare form of cancer, with approximately 560 new cases diagnosed each year, representing 0.2% of all new cancer diagnoses in the UK. It has a bimodal incidence profile, affecting both children and adults. Chondrosarcoma is the type of primary bone cancer most diagnosed in adulthood; osteosarcoma and Ewing sarcoma are the most common forms affecting children and young adults. 28% of all newly diagnosed patients are children and teenagers. Primary bone cancer represents 4% of all childhood cancers in the UK[1].

560 NEW CASES DIAGNOSED **EACH YEAR**

4% OF ALL CHILDHOOD CANCERS IN THE UK

0.2% OF ALL NEW CANCER DIAGNOSES IN THE UK



OF ALL NEWLY DIAGNOSED PATIENTS **ARE CHILDREN AND TEENAGERS**

The Bone Cancer Research Trust

In 2004, a group of families who had lost children and young people to primary bone cancer came together. They wanted to tackle the problem head on; the fact that there was virtually no accessible bone cancer information and practically no funding for research into this disease.

Determined not to accept the status quo, the families pooled funds they had already raised, and together with guidance from Professor Ian Lewis (Consultant Paediatrician and Adolescent Oncologist at St James's University Hospital, Leeds), the Bone Cancer Research Trust was registered in 2006.

Today, the Bone Cancer Research Trust is the leading charity dedicated to fighting primary bone cancer. Our mission is to save lives and improve outcomes for people affected by primary bone cancer through research, information, awareness and support.

Dr Zoe Davison, Head of Research, Information and Support

Foreword

In July 2017, the Bone Cancer Research Trust launched a new 2017 – 2022 strategy, *The Biggest Ever Commitment To Primary Bone Cancer,* outlining a number of key strategic aims and objectives across our charitable pillars of research, information, awareness and support.

This report is part of the delivery of our awareness objectives, specifically around the education of healthcare professionals and the public on the signs and symptoms of primary bone cancer.

For many years, patients have continued to report problems with diagnostic delays. One quote from a past osteosarcoma patient, aged just 14 years at diagnosis, has always been particularly haunting:

> ***"When I was finally diagnosed, I didn't know if I could go through the treatment. We had fought so long; I didn't know if I had any fight left in me.***

No patient, particularly a child, should be left so exhausted from battling to get a diagnosis that they cannot face the gruelling treatment ahead of them. Unfortunately, this is not an isolated case but something that is common for many primary bone cancer patients.

This report, which is the most comprehensive analysis of the diagnostic experiences for primary bone cancer patients to date, will be the foundation for our largest ever educational campaign. Aimed at medical professionals, it will focus on the signs, symptoms and referral pathways for primary bone cancers in the UK.

The primary objective of this report, and the research contained within, is to improve outcomes for patients and ultimately save lives through earlier diagnosis. It is our hope that this data will also help to inform future clinical guidelines to ensure diagnostic targets are met and allow patients to have an improved diagnostic experience.

Executive summary

The problem

There have been significant advances in the early detection and diagnosis of many types of cancer, through the development of screening programmes and diagnostic biomarkers. However, these advances remain elusive for patients with primary bone cancer and tumours.

Primary bone cancers and bone tumours do not benefit from an active screening programme and there are no definitive diagnostic biomarkers. The signs and symptoms of primary bone cancers and tumours are often vague and easily mistaken for less serious conditions, such as growing pains and arthritis.

Primary bone cancers and tumours have the same annual incidence as invasive meningitis[2] (which had 754 annual reported cases in 2017-2018 and 525 in 2018-19). However, whilst the majority of GPs and medical professionals are educated to recognise the red flag symptoms of meningitis, they would not recognise those of primary bone cancers, meaning that it is likely that patients will continue to be misdiagnosed.

This lack of training and continuing issues with delayed diagnosis have contributed to survival rates for primary bone cancer being below those of other more common cancers and have remained unchanged for decades.

In a 2018 pilot survey led by the Bone Cancer Research Trust, it was found that 1 in 4 patients waited longer than 6 months to get a diagnosis. Half of respondents visited a GP more than 3 times before being given a diagnosis and 1 in 4 visited more than 7 times.

Recent data released by Public Health England[3] shows that between 2006 and 2016, 21% of bone sarcomas were diagnosed as emergency presentations and that patients diagnosed via this route had a significantly poorer outcome, in terms of overall survival, compared to those diagnosed via a GP 'Two Week Wait'. However, this data does not take into account the biology or anatomical location of the tumours, making it impossible to draw sufficient conclusions.

Guidelines for the management of bone sarcomas have been published in the literature[4] and outlined by NICE[5].

While the impact of delayed diagnosis on quality of life is well-recognised and accepted by the medical community, there is no consensus and very limited data on the impact of overall survival.

Our findings

To support our awareness objectives, the Bone Cancer Research Trust has conducted a comprehensive Patient Survey, which expands upon the outcomes of our previous consultation in 2018. The survey was available during the month of July 2020 and respondents completed the questionnaire online.

The focus of the survey was two-fold. The first objective was to gain a deeper understanding of the symptoms of primary bone cancer and the anatomical sites where they occur. The second was to understand the time to and routes to diagnosis for patients.

This research found that 26% of patients wait longer than 7 months to receive a diagnosis and 13% wait longer than a year. Many cases are missed or mistaken for other conditions, such as growing pains, sporting injuries or other musculoskeletal conditions. We have found that 76% of primary bone cancer patients receive at least 1 misdiagnosis.

Of the responses to our survey, 76% of patients initially reported symptoms to a GP and only 17% of all referrals to a specialist Bone Cancer Centre were made by a GP. Of the patients referred by A&E, 82% initially presented to a GP.

The data on routes to diagnosis has allowed us to make comparisons between the diagnostic journey for patients inside and outside the UK. Furthermore, it has brought to light some concerning statistics regarding delayed diagnosis, advanced presentation and misdiagnosis, which provide evidence to suggest that further studies need to be undertaken to fully understand the impact of delayed diagnosis.

The data collected from the Patient Survey has also allowed us to conduct a comprehensive analysis of the symptoms of primary bone cancer associated with the different types and anatomical sites of tumours.

One observation that we did not anticipate was the frequent reporting of referred pain. Of patients experiencing bone pain, 32% experienced referred pain - pain at a different anatomical location to the tumour. This emphasises the importance of imaging the correct area, which may or may not be the site of the pain.

A precedent from the HeadSmart Campaign, Early Diagnosis of Brain Tumours (headsmart.org.uk), indicates that a reduction in diagnosis time can be achieved through increased awareness. Following the publication of the NICE-accredited guidelines, The Diagnosis of Brain Tumours in Children, the HeadSmart Campaign was launched to improve public and healthcare professional awareness of the symptoms of brain tumours. It has made a significant impact and facilitated earlier diagnosis, reducing the total diagnostic interval from 14.4 weeks before the launch of the campaign in 2011, to 6.7 weeks in 2013[6].

The results from this Patient Survey provide the evidence for a multi-phased, targeted educational awareness campaign, aimed at both healthcare professionals and the public and a more in-depth clinical analysis of the time and route to diagnosis.

OF PATIENTS EXPERIENCING **BONE PAIN** **32%** EXPERIENCE **REFERRED PAIN**

Data analysis and methodology

We used descriptive statistics to analyse the data generated from the Patient Survey. Categorical variables are presented as numbers and percentages. Averages, median values, standard deviations, and standard errors of the mean (SEM) are reported.

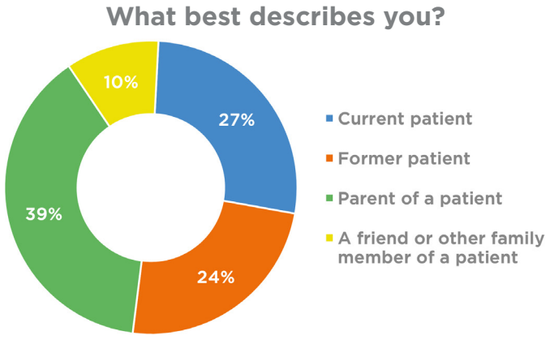
When comparing the means of two groups, Student's t-tests ($p<0.05$) were performed to ensure statistical significance. Multiple group comparisons were performed using ANOVA (Tukey test).

"THIS IS THE MOST COMPREHENSIVE STUDY OF THIS TYPE AND PROVIDES EVIDENCE TO SUBSTANTIATE THE NEED FOR AN IN-DEPTH CLINICAL STUDY.

Survey demographics

Relation to the patient

Respondents completed the survey for themselves or on behalf of a patient; 27% were current patients, 24% former patients, 39% were the parent of a patient and 10% a friend or other family member of a patient.



Location of the patient at the time of diagnosis

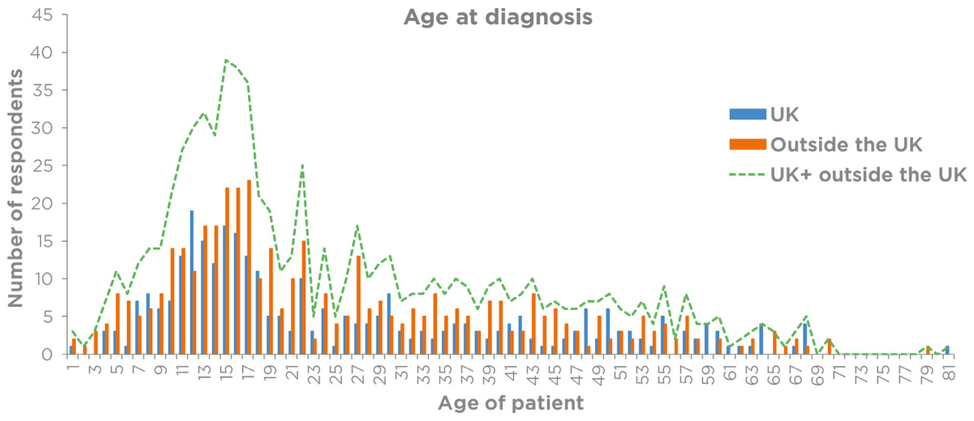
The survey collected 739 responses for primary bone cancer patients who were based in the UK (312/42%) or outside the UK (426/58%) at the time of diagnosis, plus 1 respondent for which this field was not completed (blank). Outside the UK responses include those from patients residing in the USA and other European countries, although exact details were not captured as part of the survey.

Sex

The number of female / male respondents was evenly distributed; although overall, 14% more females than males completed the survey. In the UK, 41% of respondents were male and 58% female. We understand this does not reflect the normal distribution of cases seen in primary bone cancer, which tends to affect more males than females.

Age at diagnosis

Of all respondents (UK and outside the UK combined), 210 (28%) were children (0-14 years old), 224 (30%) were teenagers and young adults (TYAs, 15-24 years old) and 303 (41%) were adults (25+ years old) at the time of their primary bone cancer diagnosis; two respondents did not indicate their age at diagnosis. Age at the point of diagnosis ranged from 1 to 81 years; the mean and median ages were 26 and 20 years respectively. For UK respondents the age at diagnosis also ranged from 1 to 81 years; the mean and median ages were 26 years and 19 years respectively. The age distribution was as expected, depending on the type of primary bone cancer, for example for osteosarcoma and Ewing sarcoma, the average ages were 19 and 16 respectively. For chondrosarcoma and chordoma the mean ages were 42 and 47 respectively.

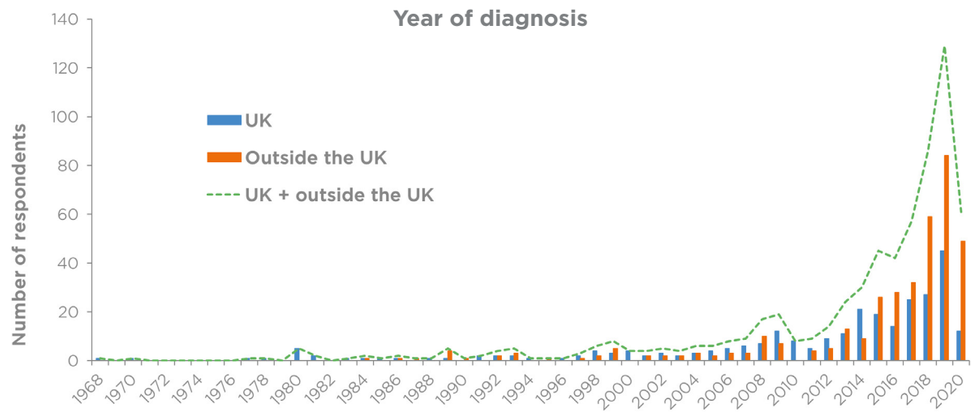


	UK	Outside the UK	Not specified location	UK + outside the UK	% UK	% Outside the UK	% UK + outside the UK
Children (0-14 years)	94	116	0	210	30.1%	27.2%	28.5%
TYAs (15-24 years)	90	134	0	224	28.8%	31.5%	30.4%
Adults (25+ years)	127	176	0	303	40.7%	41.3%	41.1%
Age not specified	1	0	1	1	0.3%	0.0%	0.1%

	Age Range	Mean	Median	Standard deviation	Standard error of the mean
UK	1-81	26.35	19	17.04	0.96
Outside the UK	1-79	25.53	20	15.85	0.77
UK + outside the UK	1-81	25.88	20	16.36	0.6

Year of diagnosis

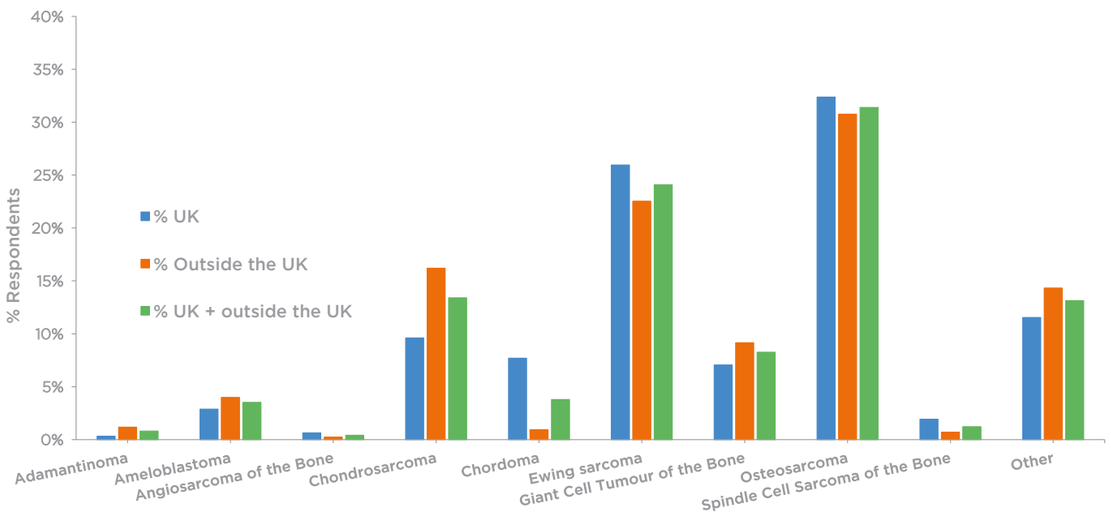
The year of diagnosis ranged from 1968 to 2020, the mean year of diagnosis was 2013 and the median year 2017.



Types of primary bone cancer

We received responses for all malignant primary bone cancers as well as for the benign tumours, ameloblastoma and giant cell tumour of the bone. The greatest number of responses regarded osteosarcoma (31%), Ewing sarcoma (24%) and chondrosarcoma (13%), the three most common primary bone tumours. Some respondents did not include the type of PBC (13%), therefore these are reported as “other”.

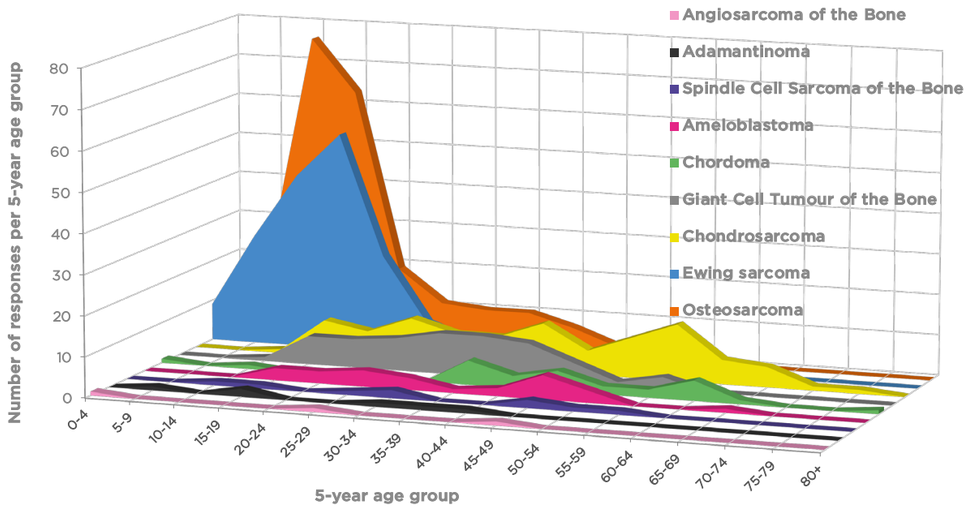
Primary bone cancer / tumour types



Primary bone cancer distribution by age

The responses by primary bone cancer type are presented below. As expected, osteosarcoma and Ewing sarcoma patients share a larger proportion of the younger population. The percentages of responses reflect, to some extent, the true incidence for primary bone cancer. The largest discrepancy was for chondrosarcoma which has an incidence of 35% of all primary bone cancers and yet made up only 13% of our responses. On the other hand, Ewing sarcoma was slightly over represented.

Primary bone cancer distribution by age



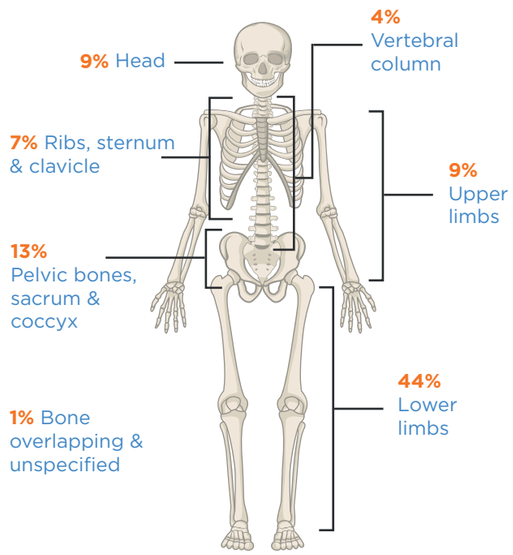
Tumour sites

Respondents described in detail the anatomical sites where their tumours occurred. All have been recorded; however, for overall analysis we have grouped them according to the ICD-10 and ICO3 (International Classification of Diseases for Oncology) site codes. Of the 739 respondents, 94 (13%) did not indicate the site of the tumour.

Anatomical sites UK + outside the UK

ICD-10 code	Number ICD-10	% ICD-10
Upper limbs (C40.0-C40.1)	64	9%
Lower limbs (C40.2-C40.3)	325	44%
Head (C41.0-C41.1)	63	9%
Vertebral column (C41.2)	31	4%
Ribs, sternum and clavicle (C41.3)	55	7%
Pelvic bones (C41.4)	99	13%
Bone, overlapping and unspecified (C40.8-C40.9, C41.8-C41.9)	8	1%
Blank answers*	94	13%
645 answers +94 blanks	739	100%

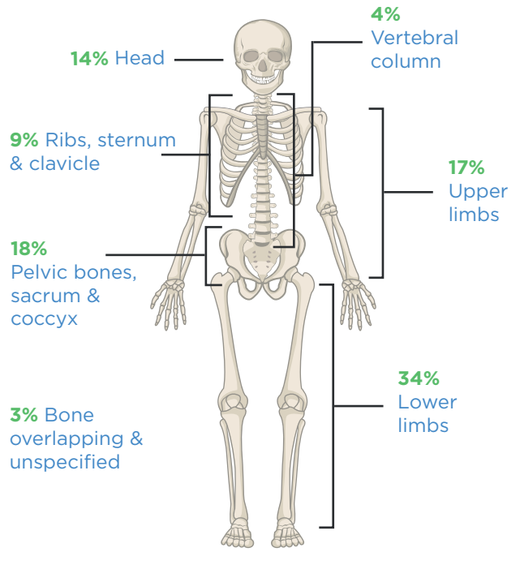
***13% did not report the location of the tumours**



The tumour site distribution of the Patient Survey is slightly different from the site incidence reported by Public Health England in 2018[7] (illustrated below). This is, however, to be expected. Our 2020 survey combines a wide range of years of diagnosis (from 1968-2020) and it does not represent a comprehensive record of the incidence for each year. It also includes a significant number of osteosarcoma and Ewing sarcoma patient respondents, for which tumours in the lower limbs were particularly prevalent.

2018 Distribution of cases diagnosed by anatomical sites (England)

ICD-10 code	Number ICD-10	% ICD-10
Upper limbs (C40.0-C40.1)	81	17%
Lower limbs (C40.2-C40.3)	164	34%
Head (C41.0-C41.1)	66	14%
Vertebral column (C41.2)	21	4%
Ribs, sternum and clavicle (C41.3)	44	9%
Pelvic bones (C41.4)	87	18%
Bone, overlapping and unspecified (C40.8-C40.9, C41.8-C41.9)	13	3%



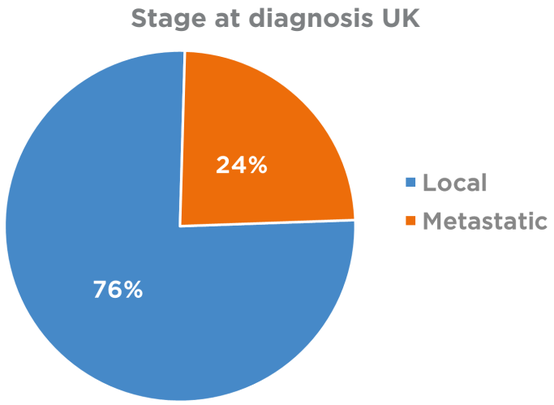
Stage at diagnosis

KEY FINDING

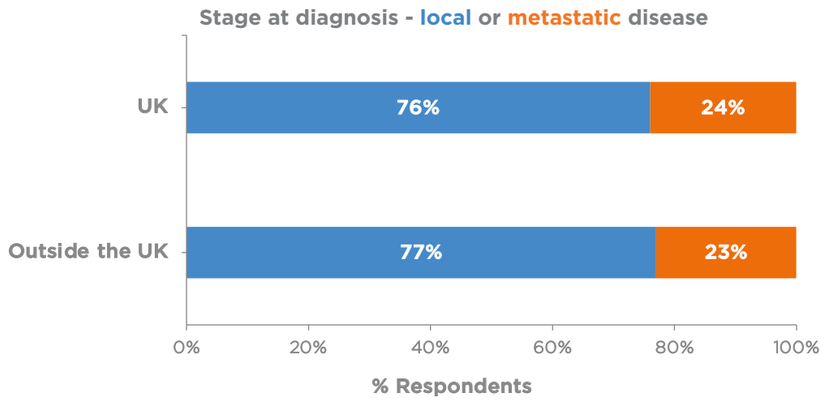
Of the 312 patients in the **UK**, 268 reported the stage of disease at diagnosis. Of these, **76% were diagnosed with local disease and 24% with metastatic disease.**

If we compare this to the patients responding from outside the UK, of the 350 patients completing this question, 77% had local disease at diagnosis and 23% metastatic disease.

These findings must be interpreted with caution and are only representative of the respondents of this survey.



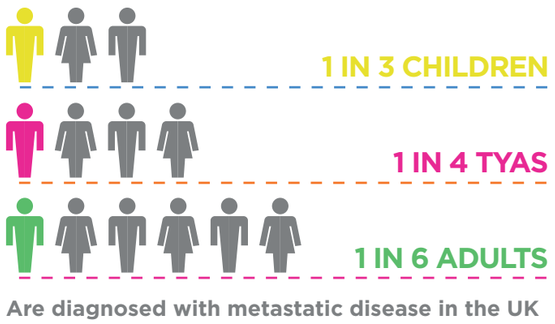
When looking at the stage at diagnosis in each age group: children, TYAs and adults, it was apparent that a higher percentage of all children diagnosed with a primary bone cancer were metastatic at diagnosis compared to adults. This was true both in patients diagnosed in the UK and outside the UK.

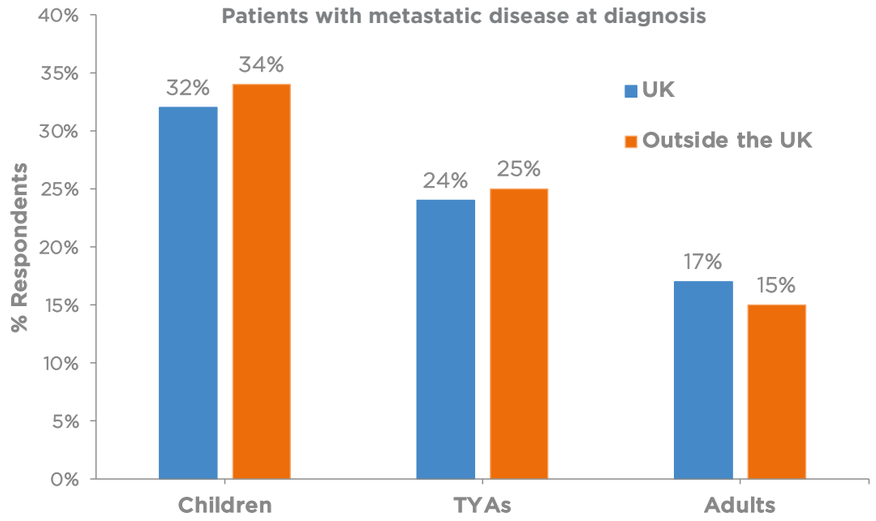


KEY FINDING

Our data suggests that **1 in 3 children in the UK are diagnosed with metastatic disease, compared to 1 in 4 TYAs and 1 in 6 adults.**

Comparing these ratios to those for patients diagnosed outside of the UK, there was only a difference noted in the ratio of adults diagnosed with metastatic disease. In the UK, 1 in 6 adults were diagnosed with metastatic disease, compared with 1 in 7 for adult patients diagnosed outside the UK.





The stage at diagnosis was also analysed by primary bone cancer type, which showed that Ewing sarcoma and osteosarcoma, were most commonly metastatic at diagnosis. These percentages, although they could be attributed to the highly aggressive nature of osteosarcoma and Ewing sarcoma, the main cancer types affecting children and TYAs, they seem higher than those reported in the literature (approximately 20%)[8]. This discrepancy can be the result of a bias selection derived from the patients who completed our survey. Nevertheless we feel this justifies further investigation.

	Osteosarcoma			Ewing sarcoma		
UK	**Local**	**Metastatic**	**Total**	**Local**	**Metastatic**	**Total**
Children	28 (68%)	13 (32%)	41	26 (68%)	12 (32%)	38
TYAs	24 (73%)	9 (27%)	33	23 (72%)	9 (28%)	32
Adults	17 (81%)	4 (19%)	21	4 (40%)	6 (60%)	10

	Osteosarcoma			Ewing sarcoma		
Outside the UK	**Local**	**Metastatic**	**Total**	**Local**	**Metastatic**	**Total**
Children	36 (67%)	18 (33%)	54	26 (67%)	13(33%)	39
TYAs	35 (78%)	10 (22%)	45	25 (58%)	18 (42%)	43
Adults	22 (79%)	6 (21%)	28	9 (90%)	1 (10%)	10

Results of the survey

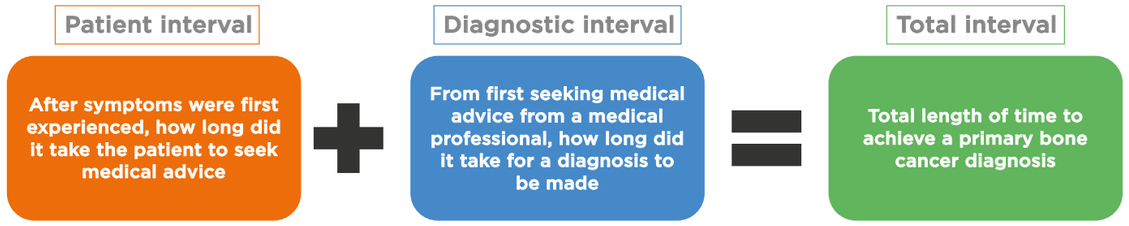
The analysis of the survey is broken down into two areas; the first covers both the time and route to diagnosis. It is important to understand the full scale of the problem regarding delayed diagnosis to measure the impact of our awareness strategy. This analysis will also allow us to identify key stakeholders to target.

The second area of analysis focuses on symptoms of primary bone tumours. It is important to understand how symptoms differ according to the type of tumour and anatomical location.

Time to diagnosis

Patient, diagnostic and total interval

The length of time required to achieve a primary bone cancer diagnosis is the combination of how long it takes for patients to seek medical advice after first experiencing symptoms – known as **patient interval**, plus the time taken for a diagnosis to be made from the point when the patient first seeks medical advice - known as **diagnostic interval**. The combination of these two periods is known as **total interval**. Long total intervals are associated with poorer outcomes, for both survival and quality of life. A late diagnosis invariably correlates with more advanced disease. Advanced disease requires more aggressive treatments (chemotherapy, surgery, and radiotherapy) which have much greater and long-lasting impact on the lives of primary bone cancer patients.



Based on literature precedent, we decided to group the responses of patient and diagnostic intervals with a cut-off point of 1 month. Many countries consider four weeks or 1 month appropriate for the diagnostic interval[9]. The NHS Waiting Time Standards For Cancer Care pledges a maximum of a Two-Week Wait to see a specialist for all patients referred with suspected cancer symptoms, and a maximum of one month (28 days for children) wait from the date a decision to treat (DTT) is made, to the first definitive treatment for all cancers[10].

Of the 739 respondents, 641 and 644 respondents completed the patient and diagnostic interval questions respectively. We grouped the answers for both patient and diagnostic intervals as ≤1 month (less than 1 month and 1 month) and >1 month (2 months +) and compared the answers in the UK with those outside the UK. We also interrogated the data to determine if there were differences for children, TYAs and adults, and isolated the responses for osteosarcoma and Ewing sarcoma patients in the UK.

Comparison by sex

Patient Interval

After symptoms were first experienced, 53% of patients sought medical advice within 1 or less than 1 month and 47% took longer than 1 month:

Patient interval	All persons	Male	Female
≤1 Month	341 (53%)	147 (55%)	194 (53%)
>1 Month	300 (47%)	122 (45%)	175 (47%)

Overall n= 641, Males n =269, Females n =369, Undeclared sex n = 3

Diagnostic interval

From first seeking medical advice from a medical professional, 40% of patients obtained a diagnosis in 1 or less than 1 month, for 60% of patients, it took longer than 1 month:

Diagnostic interval	All persons	Male	Female
≤1 Month	255 (40%)	109 (40%)	145 (39%)
>1 Month	389 (60%)	161 (60%)	226 (61%)

Overall n = 644, Males n =270, Females n =371, Undeclared sex n= 3

There was no difference between male and female respondents in either the patient or diagnostic intervals.

Diagnostic interval - comparison between UK and outside the UK

Patient interval

After symptoms were first experienced, 60% of patients in the UK and 48% of those outside of the UK sought medical advice within 1 month or less (≤1 month).

Patient interval	All	UK	Outside the UK
≤1 Month	341 (53%)	165 (60%)	176 (48%)
>1 Month	300 (47%)	112 (40%)	187 (52%)

Overall n = 641, UK n = 277, Outside the UK n = 363, Undeclared location n = 1

The larger percentage of UK patients who sought medical advice within one or less than one month after experiencing symptoms, in comparison to outside the UK, is a positive sign. The average length of patient interval for UK respondents was 84.87 days (2.8 months). Outside the UK it was 105.4 days (3.5 months), a difference that is statistically significant (p=0.048).

Diagnostic interval

KEY FINDING

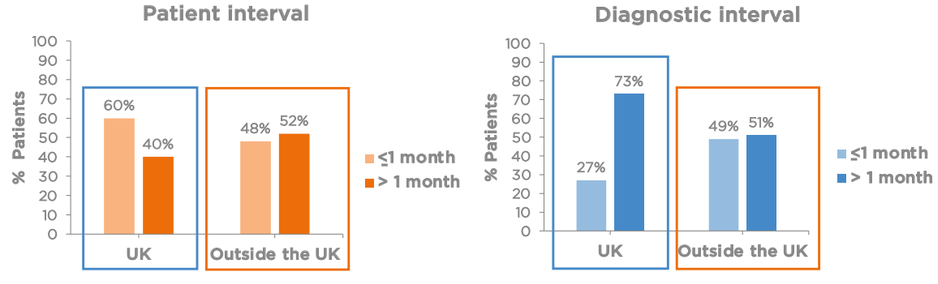
From first seeking advice from a medical professional, **27% of patients in the UK and 49% outside the UK received a diagnosis within 1 month or less (≤1 month).**

Diagnostic interval	All	UK	Outside the UK
≤1 Month	255 (40%)	75 (27%)	179 (49%)
>1 Month	389 (60%)	204 (73%)	185 (51%)

Overall n = 644, UK n = 279, Outside the UK n = 364, Undeclared location n = 1

KEY FINDING

Recent literature described the diagnostic intervals for sarcoma patients in the Netherlands; more than half of the Dutch respondents, reported a patient interval (60%) or diagnostic interval (55%) of >1 month[11]. Our data **suggests that UK patients may wait longer for a diagnosis, compared with those outside the UK. The reasons for this difference are worthy of future investigation.**



By assigning an average of 30 days to each month and 14 days to less than one month, we were able to obtain the approximate average length of time that it took for a patient to receive a primary bone cancer diagnosis from the point after they sought medical advice (diagnostic interval).

KEY FINDING

In the UK, the average diagnostic interval was 182.7 days (6.09 months). Outside the UK was, 128.1 days (4.27 months). This difference is statistically significant (p=0.0003).

Age analysis of the patient and diagnostic intervals

We analysed the patient and diagnostic interval responses according to the respondents' ages at the time of diagnosis. A higher proportion of children (0-14 years), reported symptoms within 1 month or less compared to adult patients. This pattern was repeated in patients residing outside the UK.

UK	≤1 month	>1 month
Children	63 (76%)	20 (24%)
TYAs	47 (57%)	35 (43%)
Adults	55 (49%)	57 (51%)

Overall UK n = 277, Children n = 83, TYAs n = 82, Adults n = 112

Outside the UK	≤1 month	>1 month
Children	65 (64%)	36 (36%)
TYAs	63 (53%)	56 (47%)
Adults	48 (34%)	95 (66%)

Overall Outside UK n = 363, Children n = 101, TYAs n = 119, Adults n = 143

This indicates that patients in the UK and outside the UK diligently report symptoms and seek medical advice soon after symptoms arise - 76% of children, 57% of teenagers and young adults and 49% of adults sought medical advice in 1 or less than a month in the UK.

Once patients sought medical advice, a greater proportion of UK children were diagnosed within 1 month or less compared to TYAs and adults. This pattern was repeated for patients outside the UK, however, more TYAs and adult patients outside the UK received a diagnosis in 1 month or less.

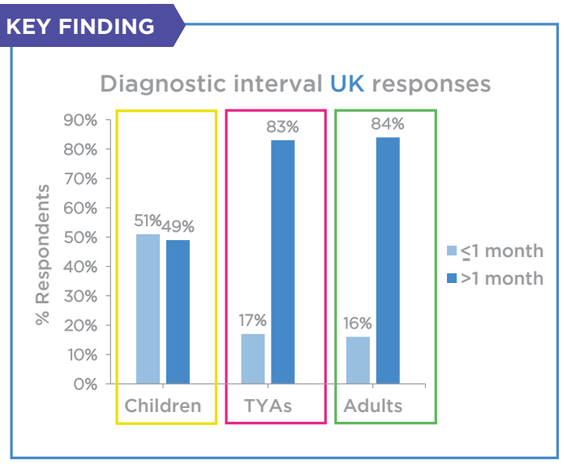
UK	≤1 month	>1 month
Children	43 (51%)	41 (49%)
TYAs	14 (17%)	68 (83%)
Adults	18 (16%)	95 (84%)

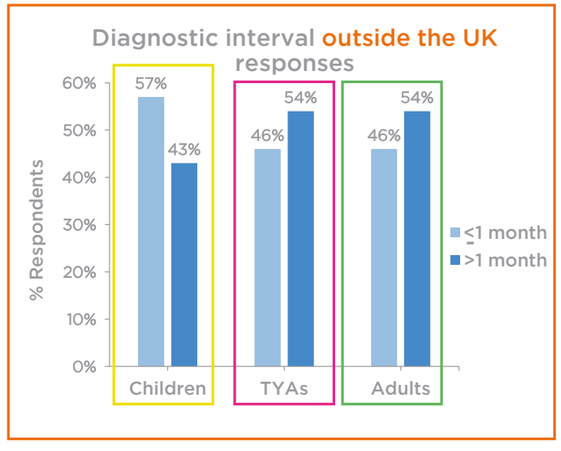
Overall UK n = 279, Children n = 84, TYAs n = 82, Adults n = 113

Outside the UK	≤1 month	>1 month
Children	58 (57%)	43 (43%)
TYAs	54 (46%)	64 (54%)
Adults	67 (46%)	78 (54%)

Overall Outside UK n = 364, Children n = 101, TYAs n = 118, Adults n = 145

KEY FINDING





Osteosarcoma responses, patient and diagnostic intervals - UK

In the UK, there were 101 respondents affected by osteosarcoma.

Patient and diagnostic interval - osteosarcoma patients UK:
The percentage of UK osteosarcoma patients who sought medical advice after experiencing symptoms and received a diagnosis was:

Patient interval	Osteosarcoma
≤1 Month	68 (67%)
>1 Month	32 (32%)
Undeclared	1 (1%)

Diagnostic interval	Osteosarcoma
≤1 Month	37 (37%)
>1 Month	64 (63%)

Osteosarcoma patients n= 101, Undetermined Patient interval n = 1

Patient interval - osteosarcoma patients UK/age analysis:
Of the 101 osteosarcoma respondents in the UK, 43 were children, 36 TYAs, 22 Adults. Note that 1 patient (2% of children) with osteosarcoma in the UK did not report how long it took them to seek medical advice after experiencing symptoms.

77% of children, compared to 58% TYAs and 64% adults, reported their symptoms in ≤1 month. 21%, 42% and 36% respective did so in >1 month (2 months+).

Osteosarcoma patients UK	≤1 month	>1 month	Blank
Children	33 (77%)	9 (21%)	1 (2%)
TYAs	21 (58%)	15 (42%)	
Adults	14 (64%)	8 (36%)	

UK osteosarcoma patients n= 101, Children n = 43, TYAs n= 36, Adults n = 22

KEY FINDING

Diagnostic interval - osteosarcoma patients UK/age: 56% of children osteosarcoma patients in the UK, compared to 28% TYAs and 14% adults, obtained a diagnosis in ≤1 month after seeking medical advice, 44%, 72% and 86% respective did so in >1 month (2 months+).

Osteosarcoma patients UK	≤1 month	>1 month
Children	24 (56%)	19 (44%)
TYAs	10 (28%)	26 (72%)
Adults	3 (14%)	19 (86%)

UK osteosarcoma patients n= 101, Children n = 43, TYAs n= 36, Adults n = 22

Ewing sarcoma responses, patient and diagnostic intervals - UK

In the UK, there were 81 respondents affected by Ewing sarcoma. For these patients, the diagnostic interval was particularly poor.

Patient and diagnostic interval - Ewing sarcoma patients UK:
The number of UK Ewing sarcoma patients who sought medical advice after experiencing symptoms and received a diagnosis was:

Patient interval	Ewing sarcoma
≤1 Month	52 (64%)
>1 Month	29 (36%)

Diagnostic interval	Ewing sarcoma
≤1 Month	19 (23%)
>1 Month	62 (77%)

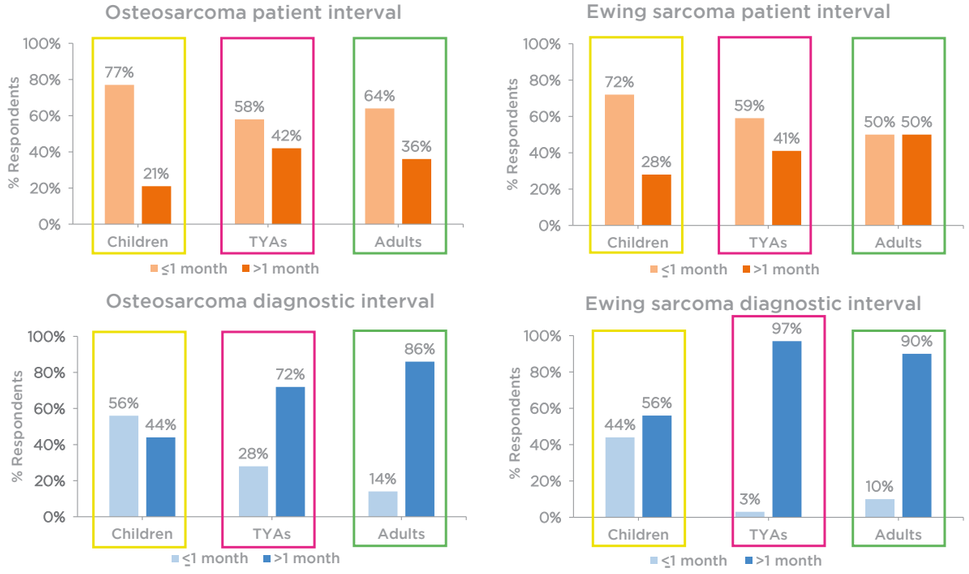
UK Ewing sarcoma patients n= 81

Patient interval - Ewing sarcoma patients UK/age:
Of the 81 Ewing sarcoma respondents in the UK, 39 were children, 32 TYAs, 10 adults at the time of diagnosis.

72% of children, compared to 59% TYAs and 50% adults reported their symptoms in ≤1 month, 28%, 41% and 50% respective did so in >1 month (2 months+).

KEY FINDING

Diagnostic interval - Ewing sarcoma patients UK/age:
Children with Ewing sarcoma were diagnosed in a more timely manner than their TYA and adult counterparts. 44% of Ewing sarcoma patients aged 0-14 in the UK, compared to 3% TYAs and 10% adults, obtained a diagnosis in ≤1 month after seeking medical advice. 56%, 97% and 90% respectively did so in >1 month (2 months+).



We calculated the average lengths for the patient, diagnostic and total intervals for osteosarcoma and Ewing sarcoma patients. The patient intervals were 1.93 and 2.03 months for Ewing sarcoma and osteosarcoma repectively. The diagnostic intervals were 6.34 and 4.41 months for Ewing sarcoma and osteosarcoma respectively and the total intervals were 8.27 months and 6.44 months for Ewing sarcoma and osteosarcoma. Whether the difference in diagnostic interval and hence total interval between Ewing sarcoma and osteosarcoma is the result of the specific set of answers we received, or due to biological deferences, making Ewing sarcoma more difficult to biopsy and confirm irrefutably, remains to be confirmed. This result would suggest that more work is needed in the laboratory to reduce this delay.

Total interval

The responses from the survey have highlighted differences in patient and diagnostic intervals between the UK and other countries. Yet when looking at local versus metastatic disease at the time of diagnosis, we have observed very little difference between UK and patients outside the UK (76% local/24% metastatic in the UK and 78% local/23% metastatic outside the UK). Both aspects, patient and diagnostic intervals, need to be optimised to achieve earlier diagnosis.

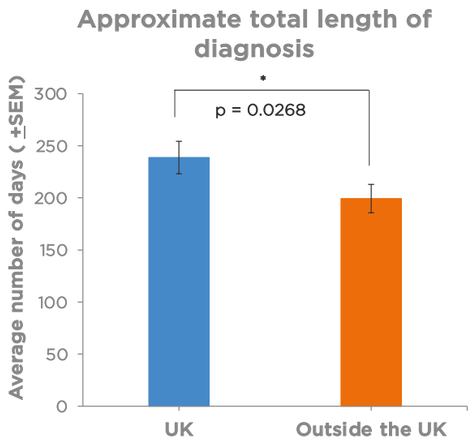
Patients in the UK seem to seek medical advice sooner, yet their diagnosis takes longer to be confirmed than for their counterparts outside the UK.

We thought that it was important to investigate if the difference in patient and diagnostic intervals, between the UK and outside the UK, result in similar total intervals.

In order to calculate the total interval, we must combine for each respondent, the length of time it took them to attend a healthcare professional, and the length of time it took for a diagnosis to be made. The responses were in text format, so we decided to convert each answer to a number of days as indicated in the table below. The patient and diagnostic intervals were combined to obtain an approximate length of diagnosis (total interval). There is, of course, an inherent error as we are assuming each answer is a round number of days/months; however, to obtain such exact level of information is probably unrealistic. Once the days were added, they were converted back to months by dividing by 30.

It has been reported that the average size of a bone tumour at presentation can be over 10cm in the UK. The mean time to diagnosis for bone tumours can range from 4 months up to 2 years, depending on the type and location of the primary tumour[12].

Obtaining the total interval for both UK and outside UK respondents allowed us to calculate an approximate average total length of diagnosis for the UK of 238.7 days (7.95 months) and 199.3 days (6.64 months) outside the UK, a difference that is statistically significant (p=0.0268).



Text in answer	Days assigned	Text in answer	Days assigned
Less than 1 month	14	12 months	360
1 month	30	13 months	390
2 months	60	14 months	420
3 months	90	15 months	450
4 months	120	16 months	480
5 months	150	17 months	510
6 months	180	18 months	540
7 months	210	19 months	570
8 months	240	20 months	600
9 months	270	21 months	630
10 months	300	22 months	660
11 months	330	23 months	690
12 months	360	24 months	720

Total interval in relation to stage at diagnosis

256 out of the 312 respondents in the UK completed the patient and diagnostic interval as well as whether they presented with metastatic or local disease when diagnosed. From this subset of the total UK responses, 203 patients (77%) had localised disease and for 62 (23%), their disease was metastatic at diagnosis.

As before, we grouped the answers to assess the effect of an early diagnosis. Although few patients (8%) were diagnosed in 1 month, only 10% were metastatic.

The proportion of metastatic disease increases with time, until it reaches the plateau of 23% (the overall percentage of the population). The lowest numbers of patients presenting with metastasis are those who reached a diagnosis early. This advantage ceases after a total interval of seven months.

Total interval	Local	Metastatic	Total
1 month	18 **(90%)**	2 **(10%)**	20 **(8%)**
2+ months	185 (76%)	60 (24%)	245 (92%)
All	203 (77%)	62 (23%)	265 (100%)

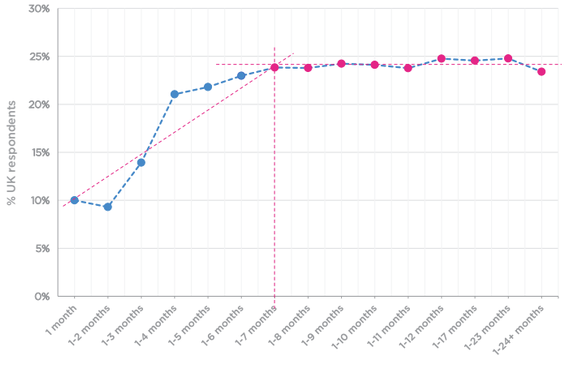
We carried out the same analysis for patients who resided outside the UK at the time of their diagnosis. 348 out of the 426 respondents outside the UK completed the patient and diagnostic interval as well as whether they presented with metastatic or local disease when diagnosed. From this subset of responses, 265 patients (76%) had localised disease and 83 (24%) presented with metastasis.

Again, we grouped the answers to assess the effect of an early diagnosis. A few more patients were diagnosed in 1 month (14%), coincidentally, the same percentage, 14%, were metastatic.

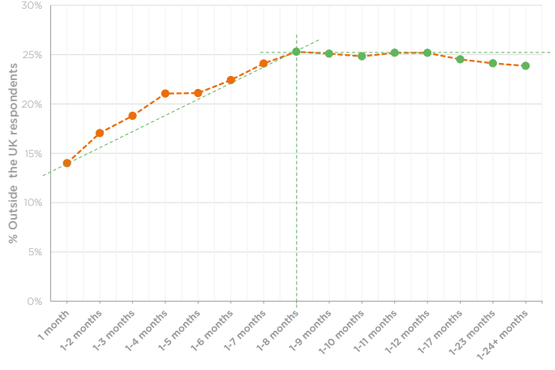
We examined increasing total interval periods and how the ratio of metastatic/local disease changed with time. When examining increasing total time of diagnosis, we see also an increase in the proportion of patients that present with advanced disease at diagnosis until a plateau is reached at a similar time to the UK.

Total interval	Local	Metastatic	Total
1 month	43 **(86%)**	7 **(14%)**	50 **(14%)**
2+ months	222 (74%)	76 (26%)	298 (86%)
All	265 (76%)	83 (24%)	348 (100%)

UK patients presenting with metastasis for increasing total intervals



Outside the UK patients presenting with metastasis for increasing total intervals



Intuitively we expect a delayed diagnosis to negatively affect the stage at which patients present.

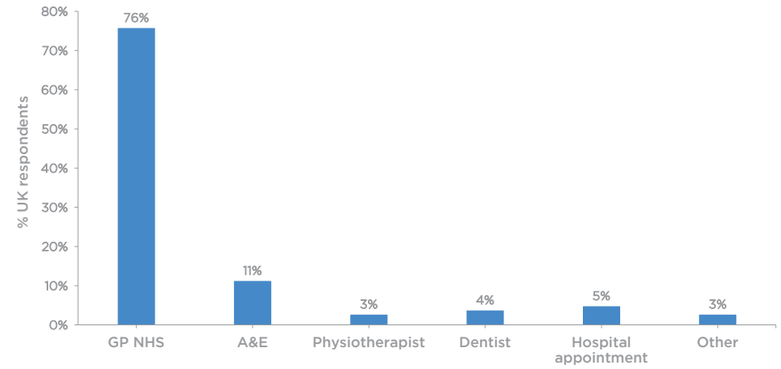
KEY FINDING

To our knowledge, the total interval analysis in connection to disease stage derived from this Patient Survey, represents the first attempt to quantify this effect for bone cancer patients.

Reporting symptoms

It is important to understand which healthcare professionals patients visit when first reporting symptoms. Out of the 312 UK patients, 279 stated which healthcare professional they first sought medical attention from. Of these 279, 76% first reported their symptoms to their GP, with 11% attending A&E. It should be noted that out of the 23 patients in the UK with a primary bone cancer or tumour in the jaw or skull, 35% first sought medical attention from a dentist.

Reporting symptoms - healthcare professional visited (UK patients)



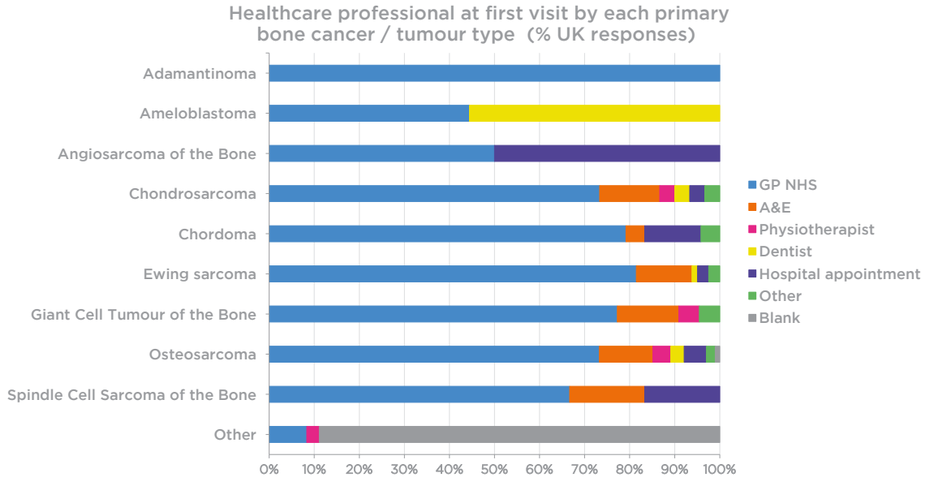
We examined the length of time taken to first report symptoms (the patient interval), for both patients first attending the GP and A&E. We noticed that patients reporting initially to A&E did so in a more timely manner.

Of the patients who indicated the time taken to first seek medical attention, 65% of patients who attended A&E did so in ≤1 month compared to 57% of those who first attended their GP.

We examined which healthcare professional patients visited for the first time, depending on the type of bone cancer / tumour they were diagnosed with. The visits to each healthcare professional are relative to the responses received for each primary bone cancer in the UK.

UK primary bone cancer distribution	Number of patients
Adamantinoma	1
Ameloblastoma	9
Angiosarcoma of the Bone	2
Chondrosarcoma	30
Chordoma	24
Ewing sarcoma	81
Giant Cell Tumour of the Bone	22
Osteosarcoma	101
Spindle Cell Sarcoma of the Bone	6
Other	36
Total	312

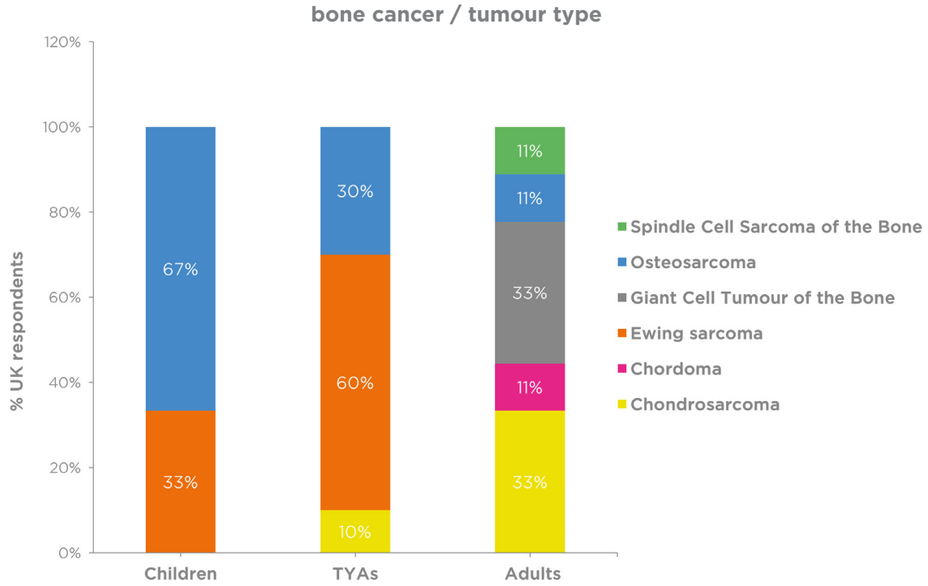
While for most forms of primary bone cancer, the majority of patients report symptoms to their GP initially, it should be noted that 56% of patients with ameloblastoma visited the dentist to initially report symptoms.



In addition, we investigated the age of patients visiting A&E in the UK and analysed the responses by each type of primary bone cancer / tumour.

Of the 11% of patients who first visited A&E after experiencing symptoms, 39% were children, 32% were TYAs and 29% were adults.

Of the children, 67% suffered from osteosarcoma and 33% with Ewing sarcoma. Of the teenagers and young adults who first visited A&E, the majority (60%) presented with osteosarcoma and a significant number (30%) with Ewing sarcoma. 33% of adults who first visited A&E were diagnosed with chondrosarcoma.

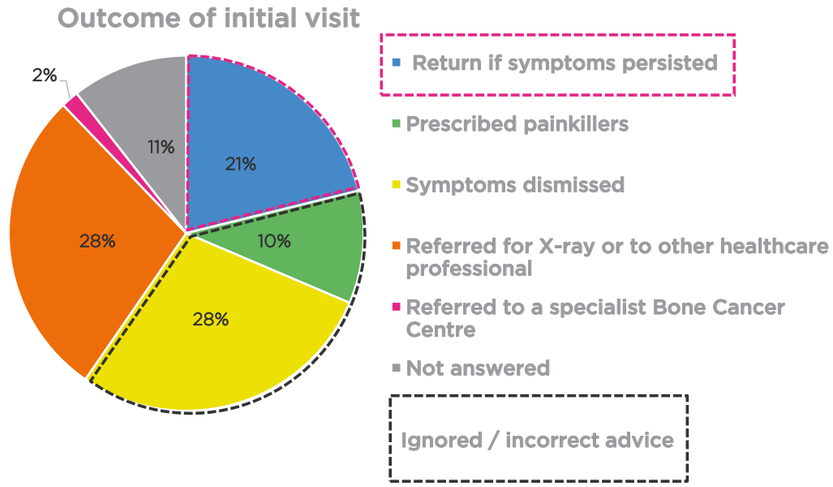


Outcome of first visit

From the UK respondents, 66 (21%) were asked to return if symptoms persisted, 32 (10%) were prescribed painkillers, yet we know they are ineffective in treating primary bone cancer pain, and 88 (28%) had their symptoms dismissed. Only 5 (2%) of the UK respondents were referred to a specialist Bone Cancer Centre directly and 88 (28%) were referred for an X-ray and / or to other healthcare professionals. Our data suggests 59% of patients had symptoms dismissed and over half of these (38%) were not asked to return if symptoms persisted. 33 respondents (11%) did not complete this question.

KEY FINDING

Overall 59% of UK respondents had their symptoms dismissed or received advice that was incorrect. As a result, patients had to return several times until they were eventually referred and received a diagnosis of primary bone cancer.

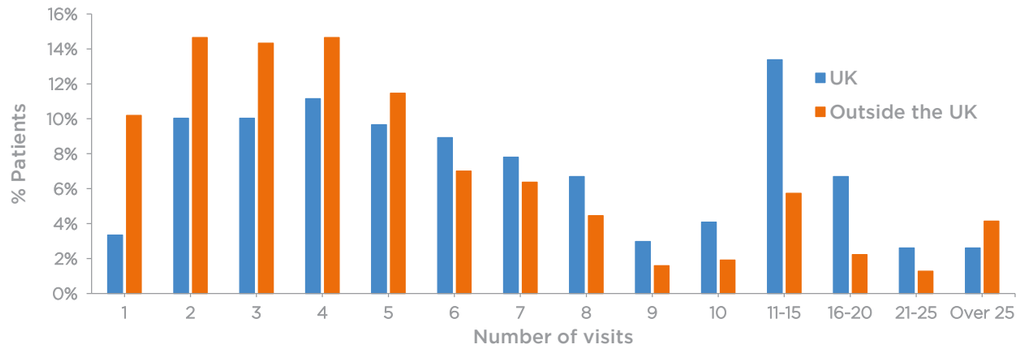


Number of visits to a healthcare professional

Respondents were asked to comment on which healthcare professionals they visited and how many times they attended before a diagnosis was made.

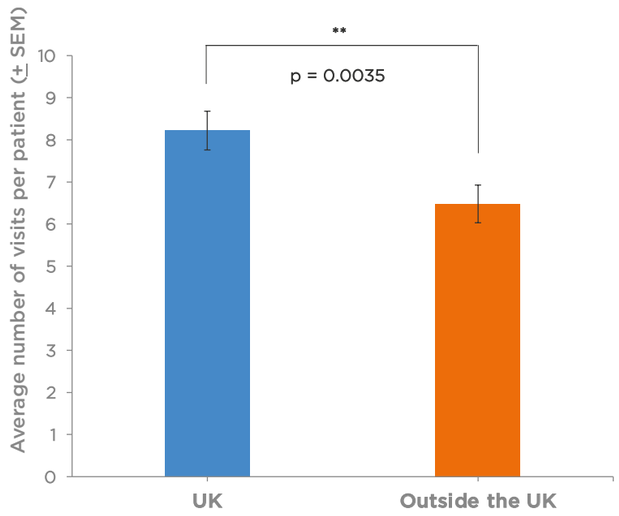
Patients in the UK and outside the UK visited one or several healthcare professionals numerous times before they obtained a referral and received a diagnosis. The number of visits ranged between 1 visit (3% in the UK and 10% outside the UK) to over 25 visits (3% in the UK and 4% outside the UK).

Number of visits per patient to a healthcare professional before diagnosis



The complete number of visits is tabulated in the appendix and a comparison between the UK and outside the UK is illustrated below.

Average number of visits to any healthcare professional per patient



KEY FINDING

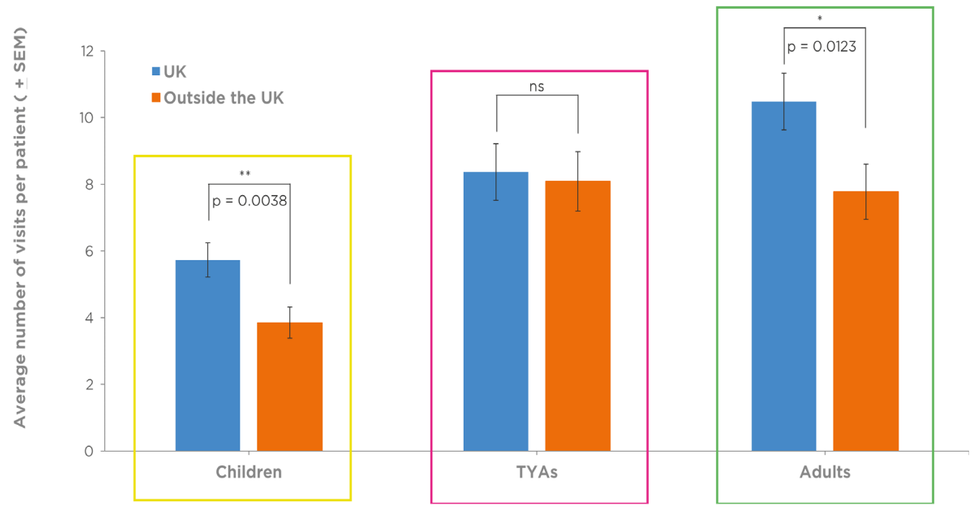
In the UK, the average was 8.2 times and outside the UK was 6.5 times. This difference is statistically significant (p=0.0035).

When grouping the responses by age, we can see that the difference in the number of visits is amplified between children living in the UK or outside the UK at the time of diagnosis.

KEY FINDING

In the UK, children visited a healthcare professional an average of 6 times, compared to 4 times outside the UK, a difference that is statistically significant (p= 0.0038). Teenagers and young adults visited a healthcare professional 8 times on average, both in the UK and abroad. Adults in the UK returned to get medical advice on average 10 times, compared to 8 times outside the UK. Again, a statistically significant difference (p = 0.0123).

Visits per patient to a healthcare professional

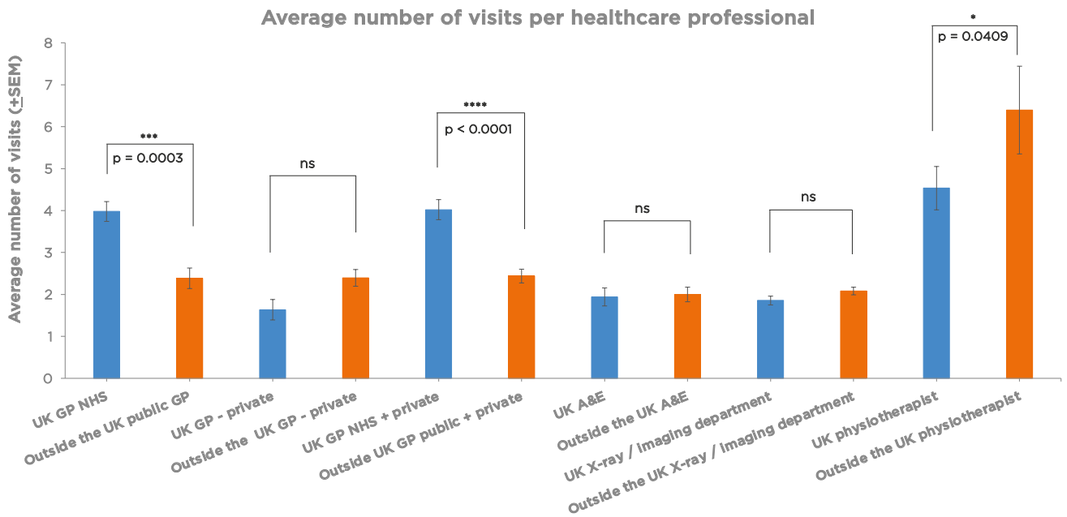


Breakdown of visits to different healthcare professionals

We analysed the responses of patients both in the UK and abroad, to determine how many times they visited different healthcare professionals before a diagnosis was made. The average number of visits to each healthcare professional are outlined below. The comparison between UK and outside UK has brought to light some interesting differences.

KEY FINDING

For example **in the UK, patients visited a GP (NHS and private) on average 4 times, whereas outside the UK, patients visited a GP (publicly funded - equivalent to NHS or private) 2.4 times. This difference is statistically significant (p=0.0003).** We found no real difference between the number of times patients visited A&E (on average 2 times), or X-ray / imaging departments; however, interestingly, patients outside the UK visited a physiotherapist over 6 times, compared to over 4 times in the UK.



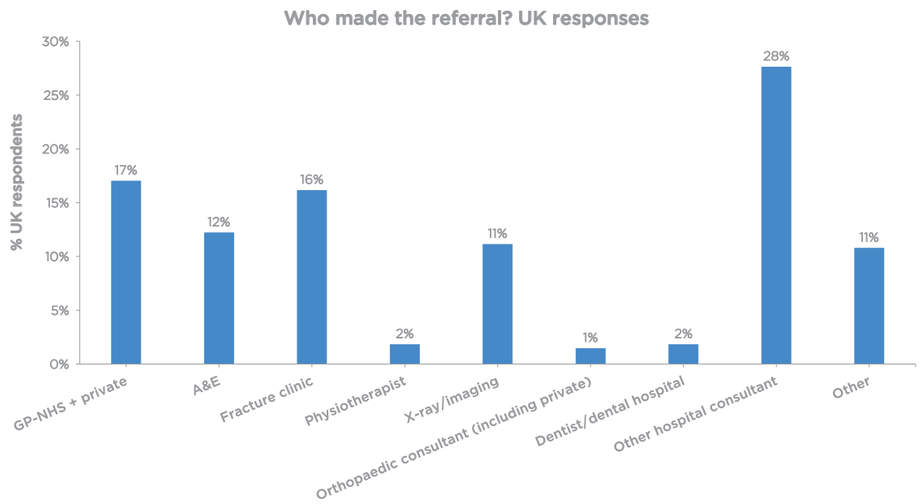
Percentage of UK patients visiting each healthcare professional

We examined the percentage of UK patients who visited each healthcare professional a certain number of times, before a diagnosis was made. 48% of UK patients visited a GP (NHS or private) between 1-3 times, 29% visited A&E between 1-3 times, and 12% of patients visited a physiotherapist also between 1-3 times. 19% of UK patients reported having visited a GP between 4-6 times and 5% between 7-12 times before a referral to secondary or tertiary orthopaedics was reached

% UK Patients	GP	GP - private	GP NHS + private	Physiotherapist	Orthopaedic / Fracture clinic	A&E	Chiropractor	Dentist	Optician	Private healthcare consultant	Other hospital consultant	X-ray / imaging department	Other
Visited 1-3 times	43.9%	3.5%	47.4%	11.9%	9.3%	29.5%	2.2%	3.2%	1.9%	9.3%	20.5%	46.8%	2.9%
Visited 4-6 times	19.2%	0.0%	19.2%	7.1%	1.3%	1.6%	1.6%	1.0%	0.0%	1.0%	2.6%	5.4%	0.3%
Visited 7-12 times	8.3%	0.0%	4.8%	2.2%	0.0%	0.6%	0.3%	0.0%	0.0%	0.0%	1.0%	0.3%	0.0%
Visited 13-25+ times	1.9%	0.0%	1.9%	0.6%	0.3%	0.3%	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.6%

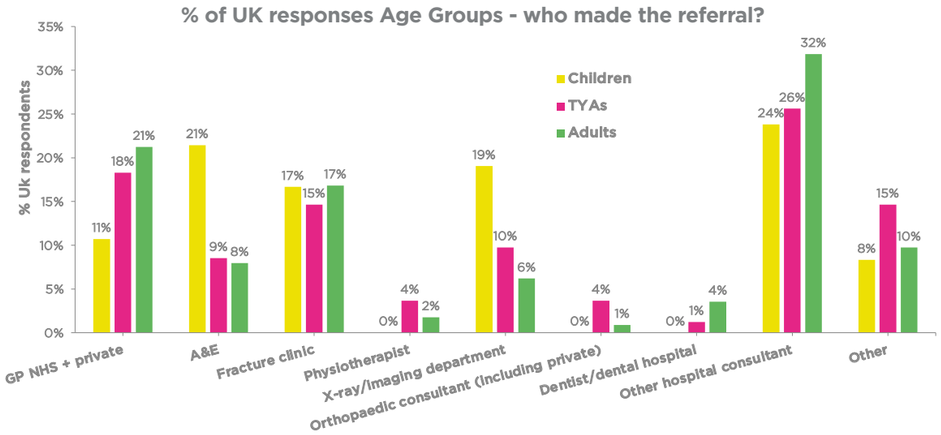
Routes to diagnosis - who made the referral?

One of the ways we investigated the routes to diagnosis for primary bone cancer patients was to enquire which medical / healthcare professional made the referral to a specialist Bone Cancer Centre in the UK.



279 patients out of the 312 possible UK respondents completed this field. Of them, 84 were children, 82 TYAs and 113 were adults at the time of their diagnosis. Overall (all ages combined), the main routes to diagnosis were hospital consultants (28%), GPs (whether NHS or private, 17%), fracture clinics (16%), A&E (12%) and X-ray / imaging department (11%).

This breakdown, however, varies significantly when we separate the responses by age. When doing so, we were struck by the high percentage of **children who were referred by A&E (21%) and X-ray / imaging (19%) routes, compared to the GP referral route (11%). For adults, these percentages are inverted; 21% and 8% respectively for GP and A&E referrals.** For TYAs, the situation is somewhere in between.

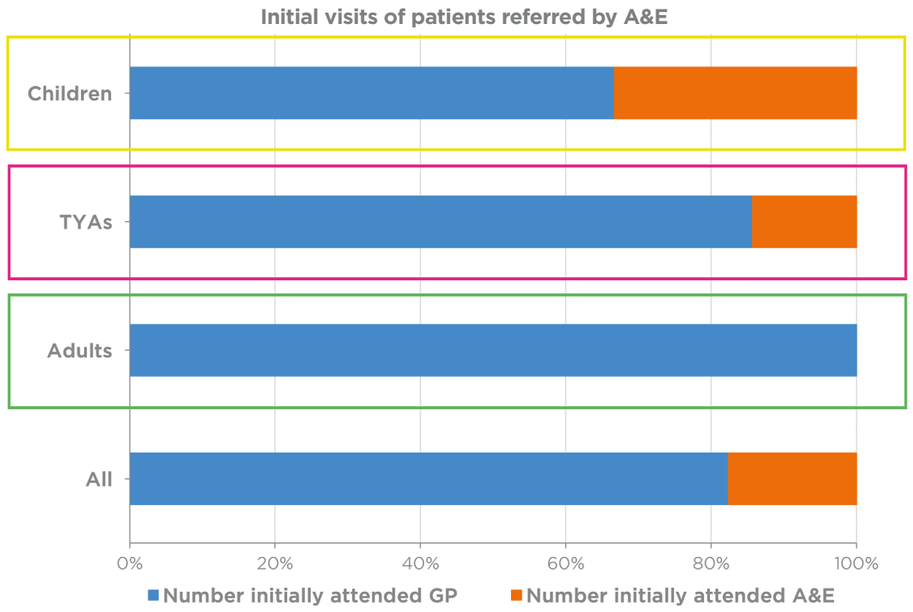


KEY FINDING

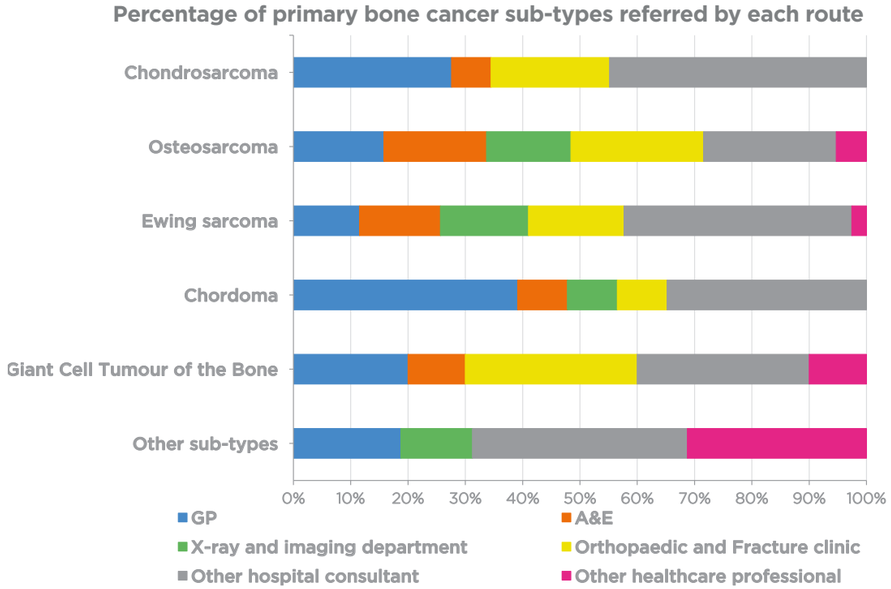
Of the patients referred to a specialist Bone Cancer Centre by A&E, 82% initially presented to a GP and only 18% went straight to an A&E department.

KEY FINDING

When looking at these results by age group, all adult patients who were referred to a specialist Bone Cancer Centre via A&E presented to a GP initially. 67% of children and 75% of TYAs who are referred by A&E initially present to a GP.

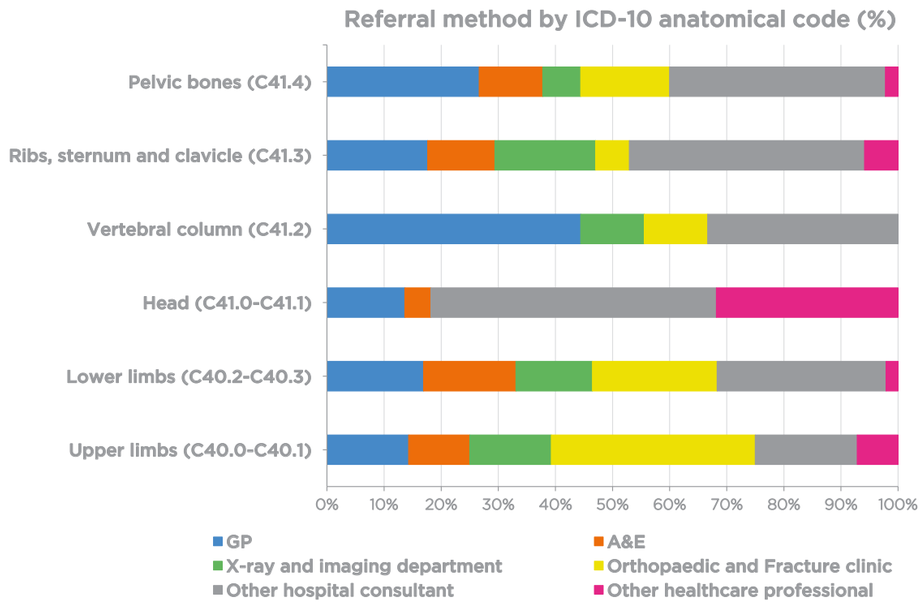


When looking at the referral route for different forms of primary bone cancer, again we noticed a large variation. 261 UK patients answered questions relating to referral route and type of primary bone cancer diagnosed. It is clear to see that the majority of chordoma cases were referred to a specialist Bone Cancer Centre by a GP (39%) and other hospital consultants (35%). Only 12% and 16% of Ewing sarcoma and osteosarcoma patients respectively, were referred to a specialist Bone Cancer Centre by a GP.

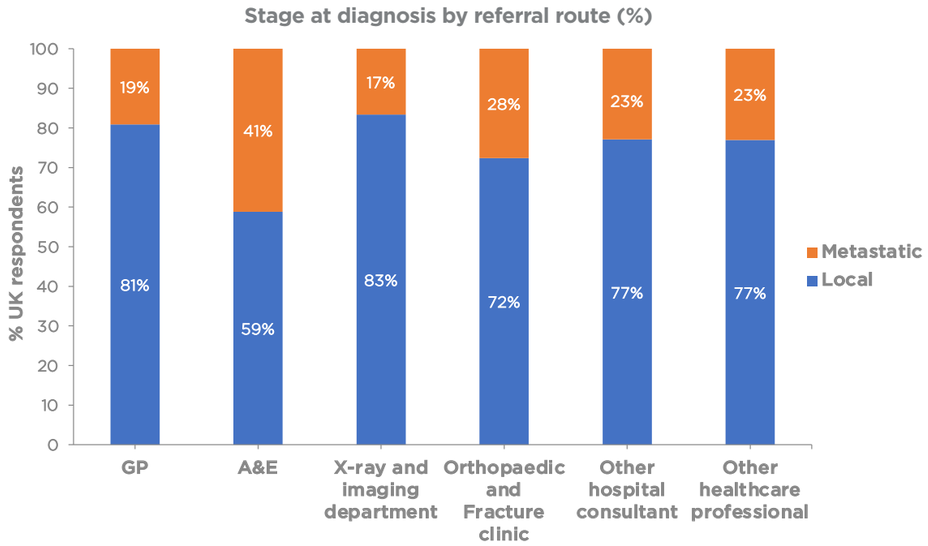


It was interesting to see that 44% of cases of the vertebral column were referred to a specialist Bone Cancer Centre by a GP, which was significantly higher than for other anatomical locations. There were less than 15% of cases of primary bone cancers in the upper limbs and head and less than 18% in cases in the lower limbs and ribs referred to a specialist Bone Cancer Centre by a GP.

Further analysis of the route to referral data allowed us to assess whether the anatomical site of the tumour had an influence on the route to referral. Of the UK patients completing the survey, 254 completed answers relating to anatomical site and route to referral and were included in the analysis.

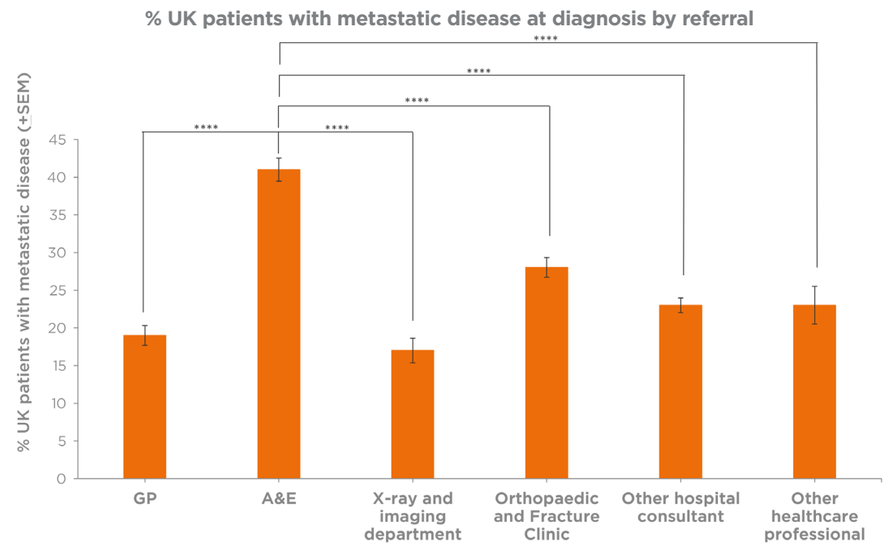


Our analysis on referral routes showed that a large proportion of patients presenting with all forms of primary bone cancer across all anatomical sites were referred by a hospital consultant not specialising in orthopaedics like rheumathology, paediatrics, general surgery. This data suggests that the symptoms experienced were wrongly diagnosed and incorrect referrals were made, which is wasteful of both time and resources.



KEY FINDING

We looked at the proportion of patients referred by each route who had either local or metastatic disease at diagnosis. **It is clear to see from this analysis that a higher proportion of patients referred via A&E were metastatic at diagnosis than patients referred by GP and all other routes, which is stastistically significant (p<0.0001).**



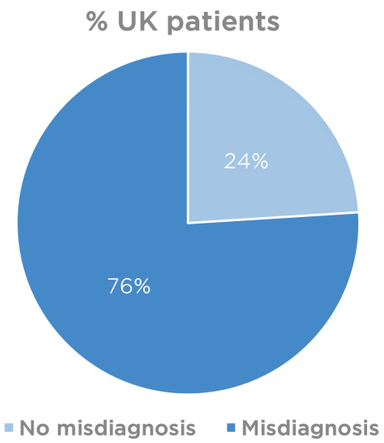
Further studies are required to understand the reasons behind this observation as factors, such as the biology of the tumour, have not been considered in this survey.

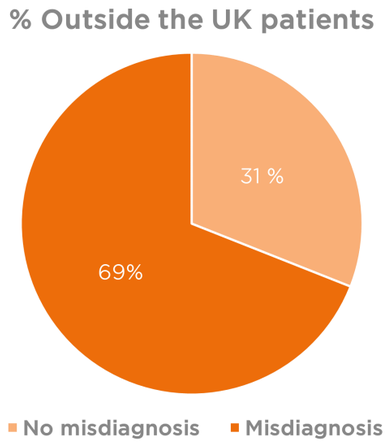
Misdiagnosis

Many patients in the UK and outside the UK received incorrect / misleading diagnoses, with some patients reporting up to 6 different alternative explanations for their symptoms. This, again, shows a lack of awareness of the symptoms of primary bone cancers.

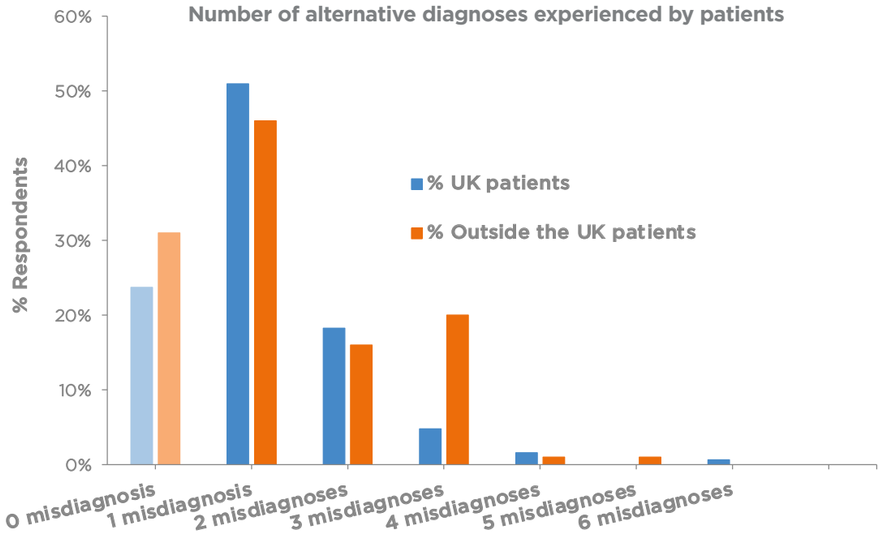
KEY FINDING

Of the 312 respondents in the UK, 74 (24%) were not given a misdiagnosis, 338 (76%) were. Of all the 426 respondents outside the UK, 132 (31%) were not given a misdiagnosis, 294 (69%) were. The figures combined (all respondents) amount to 72% of patients receiving an incorrect diagnosis for their symptoms.





Patients received from one (51% in the UK and 46% outside the UK) to six alternative explanations for their symptoms.



KEY FINDING

We analysed the number of alternative explanations patients received for their symptoms by their age at the time of diagnosis. **In the UK, 79% of children, 78% of TYAs and 73% of adults received one or more misdiagnoses.** Outside the UK, the percentages were slightly lower, but still highly significant.

	Number of misdiagnoses						
UK	**0 misdiagnosis**	**1 misdiagnosis**	**2 misdiagnoses**	**3 misdiagnoses**	**4 misdiagnoses**	**5 misdiagnoses**	**6 misdiagnoses**
Children	20 (21%)	37 (39%)	22 (23%)	10 (11%)	3 (3%)	0 (0%)	2 (2%)
TYAs	20 (22%)	44 (49%)	23 (26%)	2 (2%)	1 (1%)	0 (0%)	0 (0%)
Adults	34 (27%)	75 (59%)	14 (11%)	3 (2%)	1 (1%)	0 (0%)	0 (0%)

UK responses n = 312, Children n= 94, TYAs n = 90, Adults n = 127, age not specified n =1

Outside the UK	**0 misdiagnosis**	**1 misdiagnosis**	**2 misdiagnoses**	**3 misdiagnoses**	**4 misdiagnoses**	**5 misdiagnoses**	**6 misdiagnoses**
Children	34 (29%)	54 (47%)	22 (19%)	5 (4%)	1 (1%)	0 (0%)	0 (0%)
TYAs	35 (26%)	56 (42%)	30 (22%)	7 (5%)	3 (2%)	3 (2%)	0 (0%)
Adults	64 (36%)	98 (51%)	15 (9%)	8 (5%)	0 (0%)	0 (0%)	0 (0%)

Outside UK responses n = 426. Children n= 116, TYAs n = 134, Adults n = 176

All	**0 misdiagnosis**	**1 misdiagnosis**	**2 misdiagnoses**	**3 misdiagnoses**	**4 misdiagnoses**	**5 misdiagnoses**	**6 misdiagnoses**
Children	26%	43%	21%	7%	2%	0%	1%
TYAs	25%	45%	24%	4%	2%	1%	0%
Adults	32%	54%	10%	4%	0%	0%	0%

UK + Outside UK responses n= 738, Children n= 210, TYAs n = 224, Adults n = 303, Age = not specified n =1

In the UK key misdiagnoses were:

- **23% of children, 33% of TYAs and 9% of adults** were misdiagnosed with sporting injuries
- **43% of children and 17% of TYAs** were misdiagnosed with growing pains
- **22% of children, 17% of TYAs and 9% of adults** were misdiagnosed with a pulled muscle
- **17% of adults** were misdiagnosed with sciatica/slipped disk
- **6% of children, 3% of TYAs and 5% of adults** were misdiagnosed with arthritis
- **4% of children** were misdiagnosed with a bone infection
- **5% of children** were misdiagnosed with irritable hip

	Arthritis	**Sporting injury**	**Sciatica / slipped disk**	**Growing pains**	**Eye problems**	**Toothache / abscess**	**Bone infection**	**Headaches / Migraines**	**Irritable hip**	**Trapped nerve**	**Tendonitis**	**Pulled muscle**	**Bruising**	**Other**
Children	**6%**	**23%**	1%	**43%**	2%	1%	4%	0%	5%	1%	2%	**22%**	4%	28%
TYAs	**3%**	**33%**	2%	**17%**	1%	1%	0%	2%	0%	2%	2%	**17%**	2%	28%
Adults	**5%**	**9%**	**17%**	0%	1%	4%	0%	2%	2%	4%	2%	**9%**	2%	35%

Outside the UK key misdiagnoses were:

- **28% of children, 32% of TYAs and 12% of adults** were misdiagnosed with sporting injuries
- **23% of children and 13% of TYAs** were misdiagnosed with growing pains
- **13% of children, 21% of TYAs and 9% of adults** were misdiagnosed with a pulled muscle
- **7% of adults** were misdiagnosed with sciatica/slipped disk
- **3% of children, 6% of TYAs and 6% of adults** were misdiagnosed with arthritis
- **7% of children and 4% of TYAs** were misdiagnosed with a bone infection

	Arthritis	**Sporting injury**	**Sciatica / slipped disk**	**Growing pains**	**Eye problems**	**Toothache / abscess**	**Bone infection**	**Headaches / migraines**	**Irritable hip**	**Trapped nerve**	**Tendonitis**	**Pulled muscle**	**Bruising**	**Other**
Children	**3%**	**28%**	0%	**23%**	0%	0%	**7%**	0%	0%	1%	3%	**13%**	0%	24%
TYAs	**6%**	**32%**	6%	**13%**	1%	2%	**4%**	0%	1%	4%	4%	**21%**	2%	26%
Adults	**6%**	**12%**	**7%**	0%	1%	2%	1%	2%	1%	1%	6%	**9%**	3%	31%

KEY FINDING

Through this research we have observed that the % of children diagnosed with growing pains in the UK (43%) is almost twice that of children outside the UK (23%). Again, this suggests there is a lack of awareness around the symptoms of primary bone cancer and how these may present in different age groups.

Relationship between misdiagnosis and delayed diagnosis

We quantified the number of misdiagnoses that patients in the UK received and compared them with the length of time that it took to get a diagnosis (diagnostic interval).

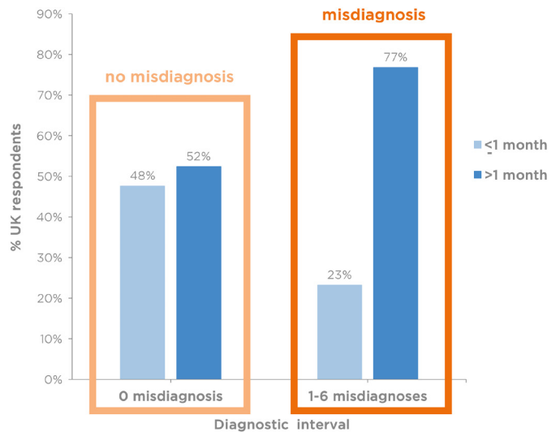
An increased number of misdiagnoses clearly delay diagnosis. We examined the differences in diagnostic interval (length of time taken to get a diagnosis who the patient seeks medical advice) for patients who reported misdiagnoses, compared to those who did not.

KEY FINDING

Only 23% of the UK patients who reported one or more incorrect diagnoses were diagnosed in ≤1 month after the patient sought medical advice.

	Effect of receiving misdiagnoses on the diagnostic interval			
Diagnostic interval	**0 misdiagnosis**	**1-6 misdiagnoses**	**% of patients with 0 misdiagnosis**	**% of patients with 1-6 misdiagnoses**
≤1 month	20	55	48%	23%
>1 month	22	182	52%	77%

Effect of misdiagnosis on the diagnostic interval

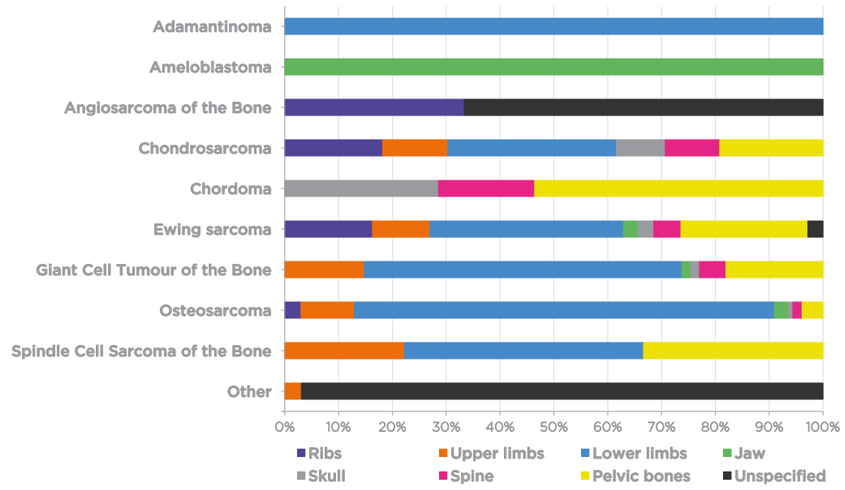


Symptoms of primary bone cancer

The data extracted from the survey has allowed us to perform a detailed analysis of the symptoms associated with primary bone cancer, depending on the **tumour type and the anatomical site where it occurred.**

Firstly, we analysed data received for each type of primary bone cancer and tumour and studied their anatomical locations.

Tumour sites by primary bone cancer / tumour type



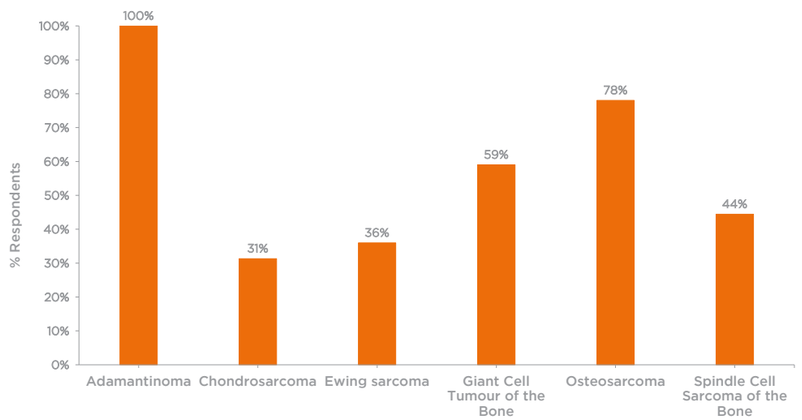
PBC in the lower limbs

Of the 739 respondents, 325 (44%) suffered from tumours in the lower limbs.

Lower limbs tumour demographics:
41% of male and 46% of female respondents had lower limb tumours.
55% of children, 47% of TYAs and 34% of adult respondents presented with tumours in the lower limbs.

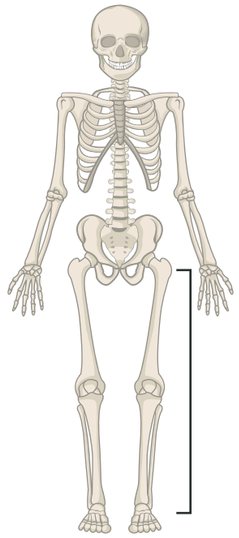
Lower limbs tumour – type of primary bone tumour:
78% of osteosarcoma, 59% of giant cell tumour of the bone, 44% of spindle cell sarcoma of the bone, 36% of Ewing sarcoma, 31% of chondrosarcoma and all adamantinoma patients had tumours in the lower limbs.

Primary bone cancer types occurring in the lower limbs



Lower limbs

Key symptoms of lower limb tumours - % of patients with tumours in the lower limbs reporting:



PAIN
- 31% constant
- 59% intermittent
- 50% worse at night
- 55% intensifies with time
- 31% resistant to pain killers
- 78% at the location of the tumour
- 19% not at the location of tumour

LUMP/SWELLING
- 50% a lump could be felt
- 53% a lump could be seen
- 29% painful to the touch
- 25% hot to the touch
- 30% no lump

MOBILITY
- 58% stiffness
- 65% limp
- 37% unable to walk
- 12% muscle wasting
- 13% balance issues/falls
- 13% no issues with mobility

GENERAL
- 21% weight loss
- 11% fever/sweating
- 8% easy bruising
- 16% bone fracture
- 8% nausea
- 35% fatigue
- 12% headaches

Symptoms in the lower limbs

Pain is a major symptom. Significant numbers of patients across all ages reported pain that was: constant, intermittent, worse at night, resistant to pain killers and intensifying with time.

KEY FINDING

For most patients with tumours in lower limbs (78%), pain was felt where the tumour was located; however, a significant 19% of patients experienced pain elsewhere - referred pain.

When analysed by age, 22% of children, 15% of TYAs and 20% of adults with tumours in the lower limbs reported referred pain.

Over 50% of patients reported a **lump / swelling** that could be seen or felt and over a quarter, a swelling that was painful and felt hot to the touch. However, it is worth noting that 30% of patients presented with no lumps or swellings, therefore the absence of a lump should not be used to rule out a potential primary bone cancer diagnosis.

Restricted movement and a **limp** are key symptoms across all ages. Most patients experienced issues with mobility, but a larger percentage of adults with tumours in the lower limbs were **unable** to walk, in comparison to children and TYAs.

KEY FINDING

Fatigue is significant and common to all ages. Weight loss seems more pronounced in children and TYAs. Interestingly, headaches were reported by 12% of children, 14% of TYAs and 11% of adults with tumours in the lower limbs.

For a detailed analysis of the symptoms reported by children, TYAs and adults suffering with PBC in the lower limbs, see Appendix.

Common misdiagnoses in the lower limbs

For many patients, their symptoms were initially wrongly associated with one or more less serious conditions. These misdiagnoses were responsible for multiple visits to healthcare professionals before a diagnosis was achieved. They caused delays and added unnecessary stress to an already traumatic and difficult diagnosis journey, for patients and their families.

KEY FINDING

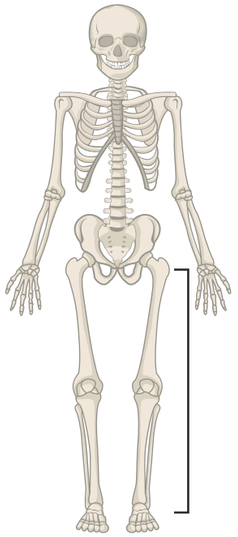
44% of children and 23% of TYAs with tumours in the lower limbs were misdiagnosed with growing pains.

34% of children, 45% of TYAs and 20% of adults with tumours in the lower limbs were misdiagnosed with sporting injuries.

22% of children and 16% of TYAs with tumours in the lower limbs were misdiagnosed with pulled muscles.

Misdiagnosis

children/ TYAS/ adults



SPORTING INJURY
34% children
45% TYAS
20% adults

GROWING PAINS
44% children
23% TYAS
0% adults

PULLED MUSCLE
22% children
16% TYAS
1% adults

ARTHRITIS
4% children
4% TYAS
8% adults

SCIATICA/SLIPPED DISK
1% children
2% TYAS
8% adults

TENDONITIS
2% children
5% TYAS
8% adults

TRAPPED NERVE
1% children
3% TYAS
3% adults

IRRITABLE HIP
3% children
0% TYAS
2% adults

BONE INFECTION
9% children
2% TYAS
1% adults

BRUISING
3% children
3% TYAS
0% adults

All responses n = 739, all males n = 317, all females n = 418, all children n = 210, all TYAS n =224, all adults n = 303, Lower limb tumours n = 325

Symptoms associated with the lower limbs by PBC type

44% of osteosarcoma patients with tumours in the lower limbs reported constant pain and pain which intensified with time, and 39% reported **pain** that was worse at night.

The larger percentage of pain in the location of the tumour was reported by osteosarcoma patients (63%), however, 12% reported pain in other locations - **referred pain**.

A lump that could be felt and seen was reported by the majority (67%) of adamantinoma patients, and over 40% of osteosarcoma patients. It is interesting to note that a **lump / swelling** that could be felt or seen (13% and 15% respectively) was experienced less commonly in patients with Ewing sarcoma in the lower limbs.

Many patients with tumours in the lower limbs reported a **limp,** (33% of adamantinoma, 20% of chondrosarcoma, 21% of Ewing sarcoma, 38% of giant cell tumour of the bone, 54% of osteosarcoma and 22% of spindle cell sarcoma of the bone patients).

Fatigue was significant and common to all PBCs, particularly for adamantinoma (33%), osteosarcoma (28%) and giant cell tumour of the bone (26%) patients with tumours in the lower limbs.

Weight loss seems more pronounced in osteosarcoma patients (16%) than for other types of PBC.

Bruising seems prominent in giant cell tumour of the bone cases of the lower limbs (11%).

Fractures seem less common in Ewing sarcoma patients (3% only) compared to, for example, 14% of osteosarcoma patients.

Headaches were reported by 11% of giant cell tumour of the bone patients with tumours in the lower limbs.

Common misdiagnoses associated with the lower limbs - PBC analysis

More chondrosarcoma patients with tumours in the lower limbs were diagnosed with **arthritis**. This is perhaps connected to the age of patients.

Across the board, patients were diagnosed with **sporting injuries** but less so for chondrosarcoma patients.

Growing pains was reported in high numbers by children suffering with Ewing sarcoma and osteosarcoma (38% and 37% respectively).

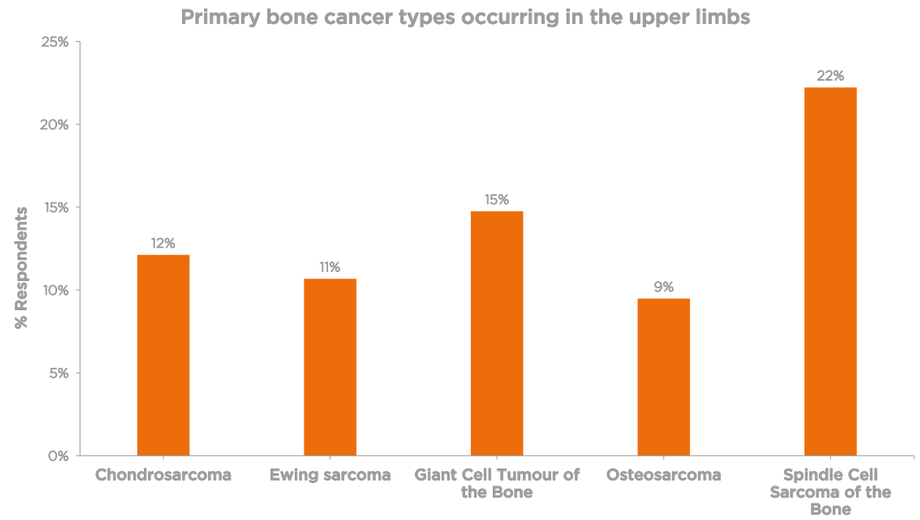
Tendonitis was particularly high for Ewing sarcoma patients with tumours in the lower limbs - 23%, compared to other types of primary bone tumours.

PBC in the upper limbs

Of the 739 responders, 64 (9%) presented with tumours in the upper limbs.

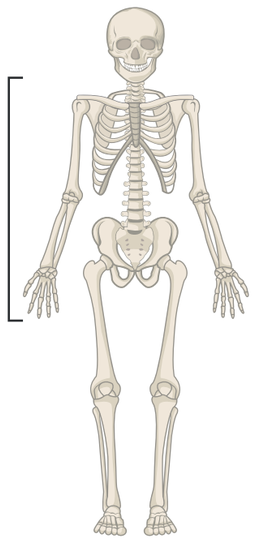
Upper limbs tumour demographics:
- 9% of male and 8% of female respondents had tumours in the upper limbs
- 11% of children, 9% of TYAs and 7% of adult respondents presented with tumours in the upper limbs

Lower limbs tumour – type of primary bone tumour:
22% of spindle cell sarcoma, 13% of giant cell tumour of the bone, 12% of chondrosarcoma, 11% of Ewing sarcoma and 9% of osteosarcoma patients had tumours in the upper limbs.



Upper limbs

Key symptoms of upper limb tumours - % of patients with tumours in the upper limbs reporting:



PAIN
- 31% constant
- 44% intermittent
- 42% worse at night
- 38% intensifies with time
- 36% resistant to pain killers
- 75% at the location of the tumour
- 17% not at the location of tumour

LUMP/SWELLING
- 50% a lump could be felt
- 52% a lump could be seen
- 20% painful to the touch
- 19% hot to the touch
- 33% no lump

MOBILITY
- 47% stiffness
- 6% muscle wasting
- 23% no issues with mobility

GENERAL
- 16% weight loss
- 14% fever/sweating
- 8% easy bruising
- 23% bone fracture
- 6% nausea
- 33% fatigue
- 8% headaches

Symptoms of the upper limbs

As is the case for tumours that occur in the lower extremities, **pain** is also a major symptom. Although we noticed that children with tumours in the upper limbs reported lower incidences of pain that was constant, intensifying with time and resistant to analgesia. Whether this is a significant difference or a consequence of a particular set of answers needs to be investigated.

Referred pain was reported by 17% of patients with tumours in the upper extremities. When analysed by age, it is notable for adults (30%) and less so for TYAs (14%) and children (9%).

Lumps / swellings that could be felt or seen were reported by over 50% of adults and TYAs, however the percentage was slightly lower for children (over 30%). As it was the case with tumours in the lower limbs, it is interesting to note that overall, 33% of respondents with tumours in the upper limbs did not actually experience any swellings / lumps.

KEY FINDING

33% of respondents with tumours in the upper limbs did not actually experience any swellings / lumps.

Restricted movement is a key symptom across all ages and **muscle wasting** was observed by some adults and TYAs, but not for children with tumours in the upper limbs.

With regard to general symptoms, **fatigue** (33% overall) is significant and common to all ages. We observed that **weight loss** appeared more pronounced in TYAs as well as nausea. Again, whether this is an artefact of a particular group of answers or a real observation, remains to be investigated.

Bone fractures are a significant symptom across all ages for patients with tumours in the upper limbs and were reported by 26% of children, 24% TYAs and 20% of adults with tumours in the upper extremities.

Headaches were reported in 9% of children, 5% of TYAs and 10% of adults with tumours in the upper limbs.

We noticed that **bruising** was reported by some adults (15%), but was not a major symptom for children and TYAs.

For a detailed analysis of the symptoms reported by children, TYAs and adults suffering with tumours in the upper limbs, see Appendix.

Common misdiagnoses for tumours in the upper limbs

Although growing pains are more often associated with pain in the legs, we noticed that 17% of children and 5% of TYAs with tumours in the upper limbs were misdiagnosed with growing pains.

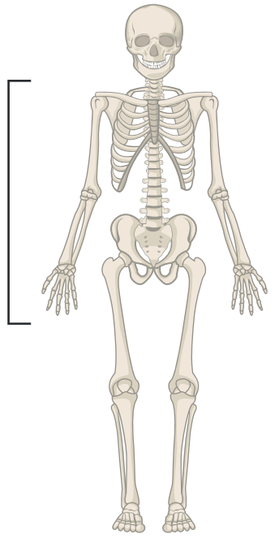
KEY FINDING

It is not a surprise to see that initially, 30% of children, 33% of TYAs and 15% of adults with tumours in the upper limbs were misdiagnosed with sporting injuries.

In addition, 17% of children, 24% of TYAs and 10% of adults with tumours in the upper limbs were misdiagnosed with **pulled muscles** and 13% of children and 5% of TYAs and 15% of adults were misdiagnosed with **tendonitis.**

Misdiagnosis

children/ TYAS/ adults



SPORTING INJURY
30% children
33% TYAS
15% adults

GROWING PAINS
17% children
5% TYAS
0% adults

PULLED MUSCLE
17% children
24% TYAS
10% adults

ARTHRITIS
0% children
10% TYAS
5% adults

TENDONITIS
13% children
5% TYAS
15% adults

TRAPPED NERVE
4% children
0% TYAS
0% adults

BONE INFECTION
4% children
0% TYAS
0% adults

BRUISING
0% children
0% TYAS
5% adults

All responces n = 739, all males n = 317, all femails n = 418, all children n = 210, all TYAS n =224, all adults n = 303, upper limb tumours n = 64

Symptoms associated with the upper limbs by PBC type

41% of osteosarcoma patients with tumours in the upper limbs reported constant pain and pain intensifying with time and 32% experienced pain that became worse at night. Intermittent pain is reported by 68% of Ewing sarcoma patients with tumours in the upper limbs.

25% of chondrosarcoma, 21% of Ewing sarcoma and 33% of giant cell tumour of the bone patients with tumours in the upper limbs reported pain in locations different to their tumours - **referred pain.**

The presence of **swelling / lump** that could be seen or felt was reported by over 50% of chondrosarcoma, Ewing sarcoma, giant cell tumour of the bone and osteosarcoma respondents with tumours in the upper limbs.

All patients with tumours in the upper limbs reported stiffness and restriction of movement; 17% of chondrosarcoma and 11% of giant cell tumour of the bone patients suffered from muscle wasting. However this was not common for Ewing sarcoma and osteosarcoma patients.

As mentioned before, **fatigue** is a significant symptom and common to all primary bone cancer types with tumours in the upper limbs.

Weight loss appeared more pronounced for Ewing sarcoma patients (32%) than for other primary bone cancer types (17% chondrosarcoma and 5% osteosarcoma), whereas **fractures** were more prominent in chondrosarcoma and giant cell tumours of the bone patients (25% and 33% respectively) with tumours in the upper extremities.

Headaches were reported by 17% of chondrosarcoma and 16% of Ewing sarcoma patients with tumours in the upper limbs.

Common misdiagnoses associated with the upper limbs - PBC analysis

More giant cell tumour of the bone patients (22%) with tumours in the upper limbs were diagnosed with **arthritis**. This is probably associated with their location, for example in the hands.

Across the board, patients were diagnosed with **sporting injuries**, osteosarcoma patients (41%) in particular, but less so for those suffering with chondrosarcoma. This could perhaps be associated with age.

Growing pains for Ewing sarcoma and osteosarcoma (16% and 9%) was a misdiagnosis associated with younger patients, less so, but in keeping with tumours in the lower extremities.

Pulled muscles A misdiagnosis of pulled muscles was signification for Ewing sarcoma (21%) and osteosarcoma (23%) patients with tumours in the upper limbs but were less relevant for chondrosarcoma patients, and absent for giant cell of the bone and spindle cell of the bone sarcoma patients.

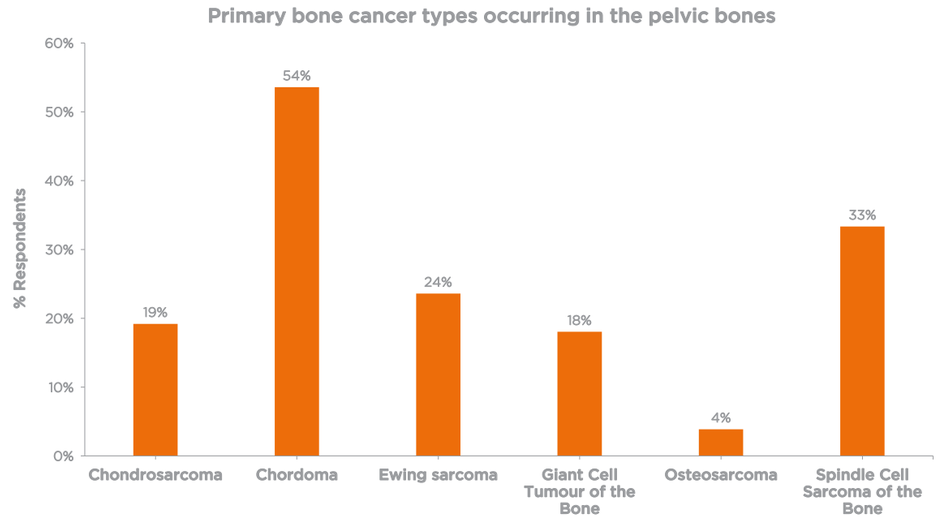
As is the case with tumours of the lower extremities, **tendonitis** was significant for Ewing sarcoma and giant cell tumour of the bone patients (16% and 22% respectively), compared to other types of primary bone tumours in the upper limbs.

PBC in the pelvic bones

Of the 739 responders, 99 (13%) presented with tumours in the pelvic bones.

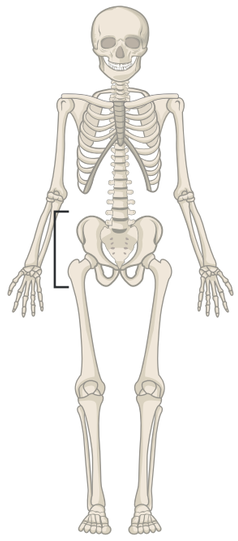
Pelvic bones tumour demographics:
16% of male and 12% of female respondents had pelvic bones tumours.
6% of children, 13% of TYAs and 19% of adult respondents presented with tumours in the pelvic bones.

Pelvic bones – type of primary bone tumour:
54% of chordoma, 33% of spindle cell sarcoma of the bone, 24% of Ewing sarcoma, 19% of chondrosarcoma, 18% of giant cell tumour of the bone and 4% of osteosarcoma patients had tumours in the pelvic bones.



Pelvic bones

Key symptoms of pelvic tumours - % of patients with tumours in pelvic bones reporting:



PAIN
- 21% constant
- 46% intermittent
- 51% worse at night
- 57% intensifies with time
- 33% resistant to pain killers
- 55% at the location of the tumour
- 40% not at the location of tumour

LUMP/SWELLING
- 21% a lump could be felt
- 21% a lump could be seen
- 3% painful to the touch
- 3% hot to the touch
- 71% no lump

MOBILITY
- 56% stiffness
- 49% limp
- 24% unable to walk
- 5% bedbound
- 7% muscle wasting
- 12% balance issues/falls
- 17% no issues with mobility

GENERAL
- 16% weight loss
- 15% fever/sweating
- 5% easy bruising
- 7% bone fracture
- 8% nausea
- 46% fatigue
- 7% headaches
- 3% bladder/bowel problems
- 4% paralysis/numbness

Symptoms in the pelvic bones

KEY FINDING

Pain is a major symptom for patients with tumours in the pelvic bones, which include the pelvis, sacrum and coccyx. 96% of patients reported some form of pain. A larger percentage reported pain that was intermittent, became worse at night and intensified with time than constant pain. This pattern is maintained across all ages. For example, 54% of children with tumours in the pelvic bones reported intermittent pain, 46% reported pain that was worse at night and 69% had pain that intensified with time. This is in comparison with 15% of children presenting were tumours in the pelvic bones that reported constant pain.

KEY FINDING

A significantly large proportion of these patients (46% of children, 41% of TYAs and 39% of adults) suffered referred pain. Although 29% of patients reported the presence of a swelling or **lump**, they were not observed in most cases (71%). This is clearly associated with the anatomical site and highlights the importance of not assuming that all bone tumours will produce a lump that could be easily observed.

KEY FINDING

The majority of patients had issues with mobility; 54% of children, 48% of TYAs and 60% of adults experienced stiffness and many (62% children, 52% TYAs, 46% adults) developed a limp. Approximately a quarter became unable to walk and a few patients (5% of adults and 7% of TYAs) became bedbound.

KEY FINDING

As with the lower and upper limbs, fatigue was reported by patients with tumours in the pelvic bones and is a major symptom across all ages (46% overall). We noticed that TYA respondents, as was the case for tumours in the extremities, experienced increased levels of weight loss, compared with children and adults.

General symptoms that are closely linked to the anatomical location of these tumours, like bladder / bowel issues and paralysis / numbness, were also reported by some patients.

For a detailed analysis of the symptoms reported by children, TYAs and adults suffering with tumours in the pelvic bones, see Appendix.

Common misdiagnoses for tumours in the pelvic bones

KEY FINDING

Many adults (37%) and TYAs (28%) were misdiagnosed with sciatica and/or nerve damage. Sporting injuries remain an important misdiagnosis, particularly among teenagers and young adults (38%) but also for children (23%).

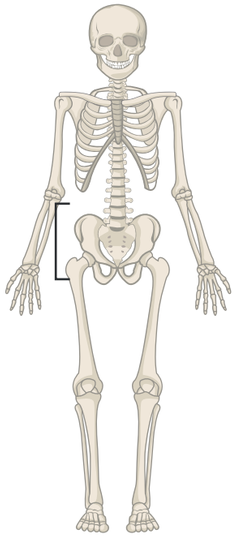
Growing pains were highlighted by 46% of children with tumours in the pelvic bones and 14% of teenagers. We speculated if the referred pain, that is commonly associated with pelvic tumours, could have influenced this incorrect diagnosis.

Arthritis was incorrectly given as an explanation for 23% of children, 14% of TYAs and 12% of adults presenting with pelvic tumours. This is significantly higher than for patients presenting with tumours in the extremities.

Irritable hip is a common childhood condition that causes symptoms such as hip pain and limping. Indeed 8% of children suffering with tumours in the pelvic bones, were incorrectly diagnosed with this condition.

Misdiagnosis

children/ TYAS/ adults



SPORTING INJURY
23% children
38% TYAS
11% adults

GROWING PAINS
46% children
14% TYAS
0% adults

PULLED MUSCLE
17% children
34% TYAS
7% adults

ARTHRITIS
23% children
14% TYAS
12% adults

TENDONITIS
0% children
3% TYAS
2% adults

TRAPPED NERVE
0% children
7% TYAS
0% adults

BONE INFECTION
0% children
10% TYAS
0% adults

BRUISING
0% children
3% TYAS
0% adults

All responses n = 739, all males n = 317, all females n = 418, all children n = 210, all TYAS n =224, all adults n = 303, pelvic tumours n = 99

Symptoms associated with the pelvic bones by PBC type

All patients, particularly those presenting with Ewing sarcoma of the pelvis, reported pain that was intermittent, worse at night and that intensified with time. Chondrosarcoma, Ewing sarcoma and chordoma patients did not report constant pain as much as osteosarcoma, spindle cell sarcoma and giant cell tumour of the bone respondents. For all primary bone cancer types, pain was described as resistant to painkillers.

KEY FINDING

Except for spindle cell sarcoma patients, approximately 40% of all primary bone cancer types patients with tumours in the pelvic bones experienced referred pain.

Although some patients (approximately 20% overall) reported lumps that could be seen or felt. 36% of chordoma, 68% of chondrosarcoma, 67% of osteosarcoma, 69% of Ewing sarcoma, 82% of giant cell tumour of the bone and all spindle cell sarcoma of the bone patients did not detect any swellings. All patients reported **issues with mobility** and over 60% of osteosarcoma patients developed a limp, with 11% of these becoming bedbound.

KEY FINDING

68% of chondrosarcoma, 44% of osteosarcoma, 50% of Ewing sarcoma, 36% of giant cell tumour of the bone and 14% of chordoma respondents described fatigue as a relevant symptom. 24% of Ewing sarcoma patients and 21% of chondrosarcoma patients experienced headaches and nausea.

Common misdiagnoses associated with the pelvic bones - PBC analysis

Around 20% of chondrosarcoma and chordoma patients with pelvic tumours were wrongly diagnosed with **arthritis**. These could be justified by their age. 17% of younger Ewing sarcoma patients received the same diagnosis.

Of the patients with pelvic tumours receiving a misdiagnosis of sporting injuries, 33% and 29% had osteosarcoma and Ewing sarcoma respectively. This could reflect the age of patients with these tumours. 11% of Ewing sarcoma and 11% of osteosarcoma patients with pelvic tumours were given **growing pains** as an alternative explanation for their symptoms.

A misdiagnosis of sciatica / nerve damage was common across all primary bone cancer types, particularly for chordoma patients which is not unexpected.

29% of Ewing sarcoma and 11% of osteosarcoma respondents with pelvic tumours received an explanation of **pulled muscle** for their symptoms.

PBC in the ribs, sternum, and clavicle

Of the 739 responders, 55 (7%) presented with tumours in the ribs, sternum and clavicle.

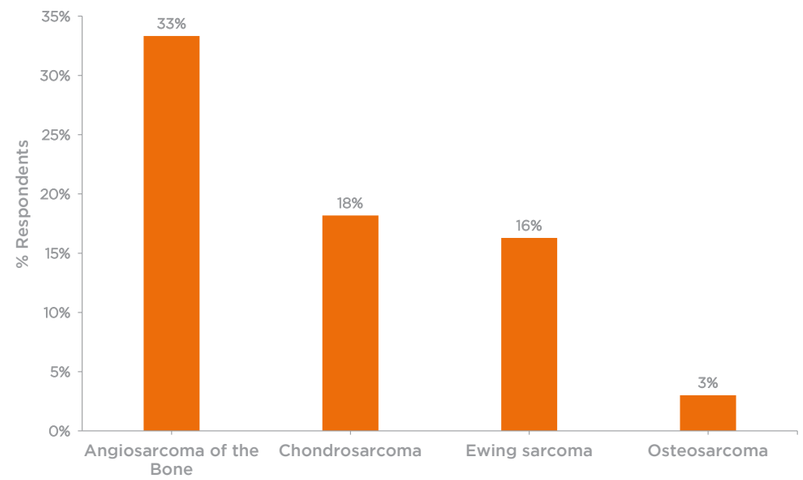
Ribs, sternum and clavicle tumour demographics

10% of male and 6% of female respondents had tumours in the ribs area.
7% of children, 8% of TYAs and 7% of adult respondents presented with tumours in the general ribs area, including sternum, clavicle and scapula.

Ribs – type of primary bone tumour

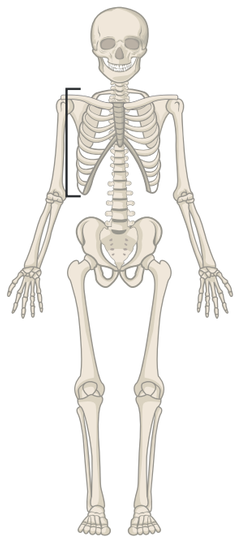
33% of angiosarcoma of the bone, 18% of chondrosarcoma, 16% of Ewing sarcoma and 3% of osteosarcoma patients had tumours in the ribs area.

Primary bone cancer types occurring in the ribs



Ribs area

Key symptoms of tumours in the Ribs - % of patients with tumours in the ribs reporting:



PAIN
- 29% constant
- 47% intermittent
- 53% worse at night
- 55% intensifies with time
- 29% resistant to pain killers
- 55% at the location of the tumour
- 18% not at the location of tumour

LUMP/SWELLING
- 49% a lump could be felt
- 40% a lump could be seen
- 22% painful to the touch
- 3% hot to the touch
- 2% red/angry looking
- 40% no lump

MOBILITY
- 31% stiffness
- 2% limp
- 2% unable to walk
- 4% bedbound
- 9% muscle wasting
- 2% balance issues/falls
- 65% no issues with mobility

GENERAL
- 20% weight loss
- 16% fever/sweating
- 4% easy bruising
- 11% bone fracture
- 2% nausea
- 36% fatigue
- 9% headaches
- 9% breathing difficulty
- 5% rash

Symptoms in the ribs

89% of patients with tumours in the ribs area experienced some form of **pain.** Across all ages, pain was described as intermittent, worse at night and intensifying with time. To a lesser extent, but still highly significant numbers of patients (approximately 30% across all age groups), described pain that was constant and / or resistant to painkillers. Most patients felt the pain in the same area where the tumour was (73% overall), yet for 21% of children and TYAs and 14% of adults, the pain was experienced elsewhere.

Over 60% of all patients with tumours in the ribs area described having a **lump or swelling** that could be seen, felt or was painful to the touch. In some cases, 7% of children, 5% of TYAs and 14% of adults reported that the lump felt hot to touch. Although many patients did develop some form of swelling, for 57% of children 42% of TYAs and 32% of adults with tumours in the rib area, this symptom was not observed.

KEY FINDING

Problems with movement were mostly associated with stiffness and this was particularly the case for TYAs (44%) and adults (32%).

As with the other tumour sites, fatigue was very common, particularly for children (50%). Weight loss was also reported by 50% of children affected by tumours in the ribs area. This was more pronounced than for TYAs (16%) and adults (5%).

Fractures were common for children and TYAs (14% and 16% respectively), but less so for adults. A particular symptom for tumours in the ribs, which is closely linked to their location, was having breathing difficulties; this was reported by 7% of children, 16% of TYAs and 5% of adults.

For a detailed analysis of the symptoms reported by children, TYAs and adults suffering with tumours in the ribs, see Appendix.

Common misdiagnoses for tumours in the ribs

KEY FINDING

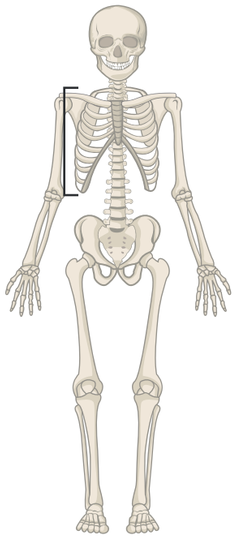
The most common alternative diagnosis for patients with tumours in the ribs area was sporting injury, particularly for younger patients (21% of children and 32% of TYAs).

A surprising discovery from the data was that, 29% of children and 11% of teenagers with tumours in the ribs were still misdiagnosed with **growing pains.**

Chest infections and asthma were reported as alternative explanations for their symptoms by young patients (14% children and 5% TYAs).

Misdiagnosis

children/ TYAS/ adults



SPORTING INJURY
21% children
32% TYAS
9% adults

GROWING PAINS
29% children
11% TYAS
0% adults

PULLED MUSCLE
0% children
37% TYAS
5% adults

ARTHRITIS
7% children
0% TYAS
0% adults

TENDONITIS
0% children
5% TYAS
5% adults

TRAPPED NERVE
0% children
11% TYAS
0% adults

BONE INFECTION
0% children
0% TYAS
5% adults

BRUISING
7% children
0% TYAS
0% adults

All responses n = 739, all males n = 317, all females n = 418, all children n = 210, all TYAS n =224, all adults n = 303, rib tumours n = 55

Symptoms associated with the ribs by PBC type

All patients with tumours in the ribs area reported **pain** which was intermittent, worse at night, intensifying with time and resistant to analgesia. A significant number of osteosarcoma (43%) and Ewing sarcoma (31%) patients and one angiosarcoma of the bone patient also reported constant pain.

For most patients, the pain was felt at the location of the tumour but not for all of them. For example, 30% of patients with chondrosarcoma located in the in the ribs felt pain somewhere else.

Chondrosarcoma, osteosarcoma and Ewing sarcoma respondents with tumours in the ribs described having **lumps** or swelling that could be seen or felt. However this is not the case for all patients. 33% of chondrosarcoma, 52% of Ewing sarcoma patients and the one angiosarcoma of the bone respondent did not develop lumps.

Restricted movement and **stiffness** were symptoms for 22% of chondrosarcoma, 29% of osteosarcoma and 34% of Ewing sarcoma patients.

Tiredness as been highlighted for the other tumour sites, is also a symptom for patients with tumours in the ribs; 22% chondrosarcoma, 43% osteosarcoma and 45% Ewing sarcoma patients, experienced **fatigue.**

Weight loss was reported by 34% of Ewing sarcoma respondents.

Common misdiagnoses associated with the ribs - PBC analysis

The main alternative explanations for the symptoms of patients with chondrosarcoma, osteosarcoma and Ewing sarcoma in the ribs, were sporting injuries and pulled muscles. 17% of chondrosarcoma, 43% of osteosarcoma and 24% of Ewing sarcoma received a misdiagnosis of a **pulled muscle.**

PBC in the spine

Of the 739 responders, 31 (4%) presented with tumours in the vertebral column.

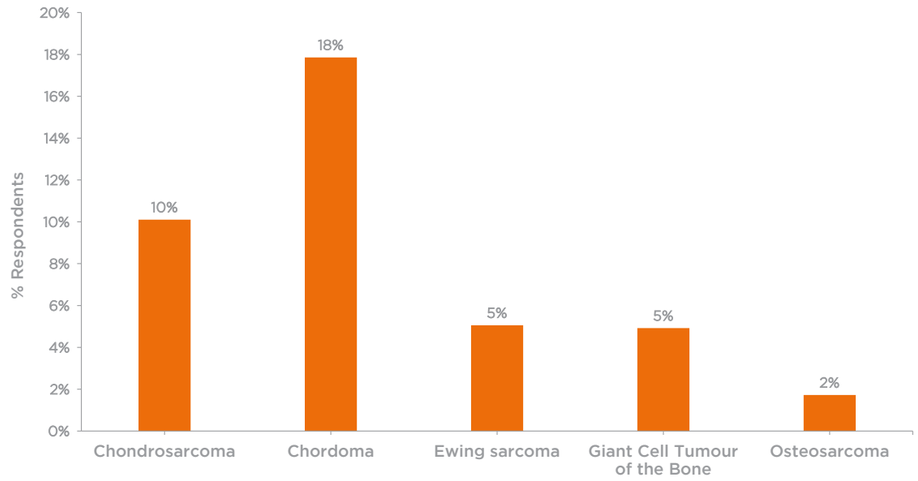
Spine tumour demographics

4% of male and 4% of female respondents had tumours in the spine.
3% of children, 3% of TYAs and 6% of adult respondents presented with tumours in the vertebral column.

Spine – type of primary bone tumour

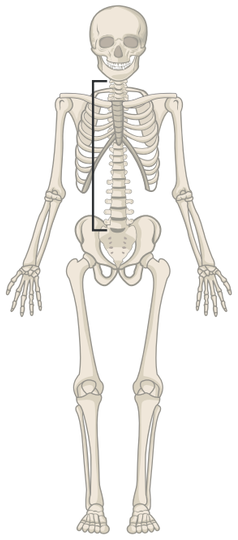
18% of chordoma, 10% of chondrosarcoma, 15% Ewing sarcoma, 5% of giant cell tumour of the bone and 2% osteosarcoma patients had tumours in the spine.

Primary bone cancer types occurring in the spine



Spine

Key symptoms of tumours in the spine - % of patients with tumours in the spine reporting:



PAIN
- 23% constant
- 39% intermittent
- 61% worse at night
- 52% intensifies with time
- 42% resistant to pain killers
- 58% at the location of the tumour
- 39% not at the location of tumour

LUMP/SWELLING
- 23% a lump could be felt
- 16% a lump could be seen
- 6% painful to the touch
- 6% hot to the touch
- 68% no lump

MOBILITY
- 58% stiffness
- 16% limp
- 26% unable to walk
- 10% bedbound
- 9% muscle wasting
- 32% balance issues/falls
- 13% no issues with mobility

GENERAL
- 23% weight loss
- 19% fever/sweating
- 10% easy bruising
- 3% bone fracture
- 6% nausea
- 55% fatigue
- 10% headaches

Symptoms in the spine

Across all ages, patients with tumours in the spine reported **pain** that can be constant or intermittent, worse at night, intensifying with time and resistant to analgesia as a main symptom.

KEY FINDING

For many (58%), the pain was felt at the location of the tumour, yet 50% of children, 43% of TYAs and 33% of adults experienced pain elsewhere - referred pain.

Although some patients developed lumps, a high proportion (67% children, 57% TYAs and 72% adults) did not.

KEY FINDING

Mobility problems are very significant across all age groups. **In addition to stiffness and restriction to movement, many patients reported issues with balance and increased falls along with numbness.**

Weight loss was reported by 43% of teenagers and young adults with tumours in the spine. **Fatigue** was also reported as a major symptom by 50% of children, 43% of TYAs and 61% of adults. Fever and headaches were also reported.

For a detailed analysis of the symptoms reported by children, TYAs and adults suffering with tumours in the spine, see Appendix.

Common misdiagnoses in the spine

We were somewhat surprised to see that children (33%) and teenagers (14%) with tumours in the spine were still given growing pains as an explanation for their symptoms. We speculated whether this could be due to referred pain, however, this would emphasise the need for further data gathering.

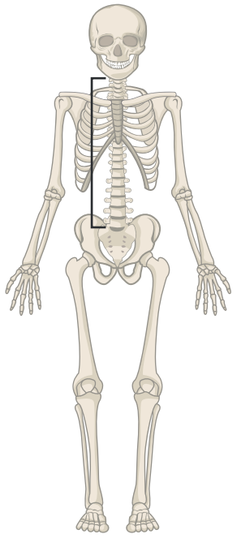
Sporting injuries were a common misdiagnosis given to 33% of children and **sciatica / slipped disk** to 28% of adults.

KEY FINDING

Pulled muscle was significant across all age groups, but particularly high (50%) for children. Scoliosis - the curvature of the spine - was mentioned as an explanation of symptoms by 14% of TYAs and 6% of adults.

Misdiagnosis

children/ TYAS/ adults



SPORTING INJURY
33% children
0% TYAS
11% adults

GROWING PAINS
33% children
14% TYAS
0% adults

PULLED MUSCLE
50% children
29% TYAS
22% adults

ARTHRITIS
0% children
0% TYAS
6% adults

SCIATICA/SLIPPED DISK
0% children
5% TYAS
28% adults

TRAPPED NERVE
0% children
0% TYAS
6% adults

All responses n = 739, all males n = 317, all females n = 418, all children n = 210, all TYAS n =224, all adults n = 303, spine tumours n = 31

Symptoms associated with the spine by PBC type

Chordoma and chondrosarcoma were the main type of primary bone cancer affecting patients with tumours in the vertebral column. They all reported pain as a main symptom and many suffered referred pain, for example 60% of chondrosarcoma and 40% of chordoma respondents.

Chondrosarcoma and Ewing sarcoma patients with tumours in the spine reported lumps that could be seen and felt, yet 80% of chordoma respondents did not develop swellings.

They all experienced issues with mobility and balance and 33% of Ewing sarcoma patients experienced muscle wasting.

KEY FINDING

Fatigue is, again, a common symptom that was reported, especially by chordoma patients (80%).

Common misdiagnoses associated with the spine - PBC analysis

Sporting injury was provided as an alternative explanation of symptoms for 20% of chordoma, 22% Ewing sarcoma and 33% giant cell tumour of the bone patients. Sciatica and / or a slipped disk were a common misdiagnosis for 60% of chordoma patients.

A pulled muscle was also a very common explanation for chondrosarcoma (20%), Ewing sarcoma (44%) and osteosarcoma patients.

PBC in the head

Of the 739 responders, 63 (9%) presented with tumours in the head. Of them, 25 were in the skull and 38 in the jaw. Although these are a small set of responses, we felt that it would be inappropriate to summarise their symptoms together. Therefore, we analysed jaw and skull separately.

Jaw tumour demographics

3% of male and 7% of female respondents had tumours in the jaw.
2% of children, 4% of TYAs and 8% of adult respondents presented with tumours in the jaw.

Jaw – type of primary bone tumour

100% of ameloblastoma, 3% Ewing sarcoma, 3% osteosarcoma and 2% of giant cell tumour of the bone patients had tumours in the jaw.

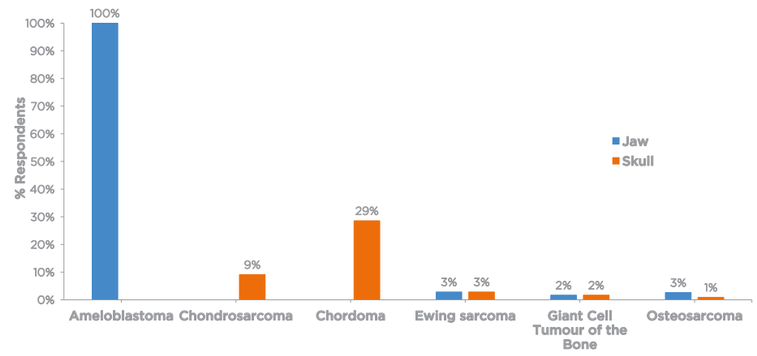
Skull tumour demographics

3% of male and 4% of female respondents had tumours in the skull.
2% of children, 3% of TYAs and 4% of adult respondents presented with tumours in the skull.

Skull – type of primary bone tumour

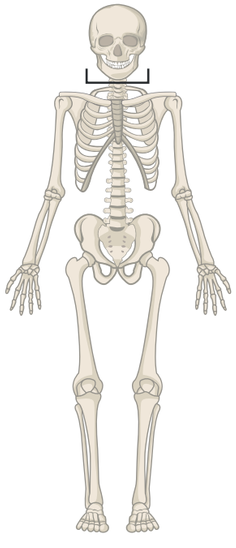
29% of chordoma, 9% of chondrosarcoma, 3% Ewing sarcoma, 2% of giant cell tumour of the bone and 1% osteosarcoma patients had tumours in the skull.

Primary bone cancer types occurring in the jaw and the skull



Jaw

Key symptoms of tumours in the Jaw -
% of patients with tumours in the jaw reporting:



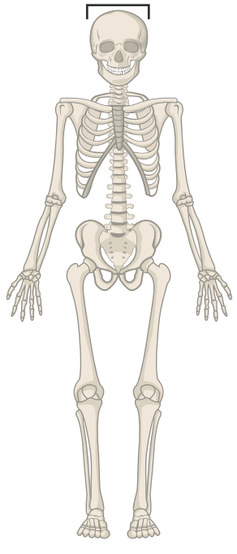
PAIN
- 16% constant
- 16% intermittent
- 8% worse at night
- 18% intensifies with time
- 42% at the location of the tumour
- 18% not at the location of tumour

LUMP/SWELLING
- 71% a lump could be felt
- 61% a lump could be seen
- 18% painful to the touch
- 16% hot to the touch
- 13% no lump

GENERAL
- 5% weight loss
- 3% fever/sweating
- 3% easy bruising
- 5% nausea
- 16% fatigue
- 13% headaches
- 42% toothaches

Skull

Key symptoms of tumours in the Skull -
% of patients with tumours in the skull reporting:



PAIN
- 16% constant
- 20% intermittent
- 12% worse at night
- 16% intensifies with time
- 12% resistant to pain killers
- 44% at the location of the tumour
- 20% not at the location of tumour

LUMP/SWELLING
- 24% a lump could be felt
- 20% a lump could be seen
- 4% painful to the touch
- 4% hot to the touch
- 56% no lump

MOBILITY
- 16% issues with balance

GENERAL
- 12% weight loss
- 12% fever/sweating
- 12% nausea
- 20% fatigue
- 60% headaches

Symptoms in the jaw and skull

The main symptom reported by patients with tumours in the jaw is pain that is often located at the site of the tumour, but can be felt elsewhere within the head and manifest as referred pain (21% overall).

A lump that can be seen or felt was reported by most respondents with tumours in the jaw (71% and 61% respectively).

KEY FINDING

Headaches were also reported, but the overwhelming type of pain reported by 56% of TYAs and 50% of adults with tumours in the jaw was toothache.

Patients with tumours in the skull also suffered pain which, although often at the site of the tumour, for 20% of patients manifested as referred pain.

Although some patients did report the presence of a lump/swelling, 56% overall and 85% of adults with tumours in the skull did not present with any swellings or lumps.

KEY FINDING

Patients with tumours in the skull did not experience issues with mobility, yet they experience increased number of falls and a loss of balance. Children and teenagers with tumours in the skull reported weight loss (20% and 14%) and fatigue (40% and 43%). Adults also suffered from nausea (23%).

All patients with tumours in the skull presented with **headaches and / or migraines.**

For a detailed analysis of the symptoms reported by children, TYAs and adults suffering with tumours in the head, see Appendix.

Common misdiagnoses in the jaw and skull

Patients with tumours in the jaw are mostly given an explanation involving a **toothache / abscess** for their symptoms. Indeed 50% of them were referred to a specialist Bone Cancer Centre by a dentist or oral consultant.

Patients with tumours in the jaw mostly received an explanation for their symptoms that was associated to dental problems, whether their tumour was malignant or benign.

For patients with tumours in the skull, headaches and migraines dominate the alternative explanations (29% of TYAs and 31% of adults).

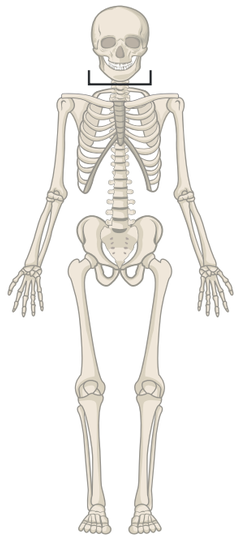
KEY FINDING

Eye problems are also a common misdiagnosis; a misdiagnosis that was offered to 43% of teenagers and young adults and 15% of adults with tumours in the skull. An alternative diagnosis of sinus or ear infection was also offered to 20% of children with tumours in the skull.

Older patients with tumours in the skull, particularly chondrosarcoma and chordoma, also received eye problems as an explanation of their symptoms. These were not common for younger patients suffering with Ewing sarcoma or osteosarcoma of the skull. Also unique to chordoma patients, was the misdirection of suffering from trapped nerves or pulled muscles.

Misdiagnosis

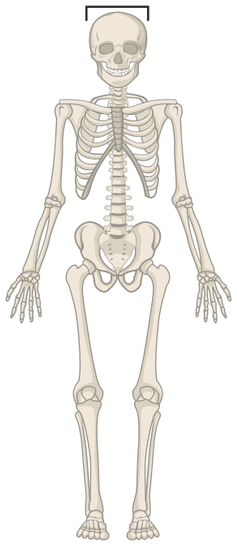
children/ TYAS/ adults



Jaw

TOOTHACHE/ABSCESS
0% children
33% TYAS
33% adults

HEADACHES/MIGRAINES
0% children
0% TYAS
3% adults



Skull

SINUS/EAR INFECTION
20% children
0% TYAS
15% adults

HEADACHES/MIGRAINES
0% children
29% TYAS
31% adults

TOOTHACHE/ABSCESS
20% children
0% TYAS
0% adults

All responses n = 739, all males n = 317, all females n = 418, all children n = 210, all TYAS n =224, all adults n = 303, Jaw tumours n = 38, Skull tumours = 25

Symptoms associated with the jaw and skull by PBC type

Tumours in the jaw

We received many responses for patients suffering from ameloblastoma. Ameloblastoma is a rare, non-cancerous tumour arising in and around the jawbone. Although their condition is very different from osteosarcoma or Ewing sarcoma, the presentation of symptoms, including pain and swelling in the jaw, appear to be similar. One key difference we observed is highlighted by the responses of Ewing sarcoma patients affected by tumours in the jaw; for 60% of them, pain intensified with time, which **was not** the case for ameloblastoma patients. Osteosarcoma and Ewing sarcoma patients also indicated that their pain was more constant than intermittent.

Tumours in the skull

A high proportion of chordomas arise in the skull. The responses from chordoma patients seem to indicate that pain is rather more constant than intermittent, compared for example, with Ewing sarcoma, chondrosarcoma or osteosarcoma patients. Chordoma patients also reported stiffness and muscle wasting, which was not indicated by other primary bone cancer patients with tumours in the skull. Whether these differences are the result of specific answers or true differences remains to be confirmed.

Treatment - type of surgery

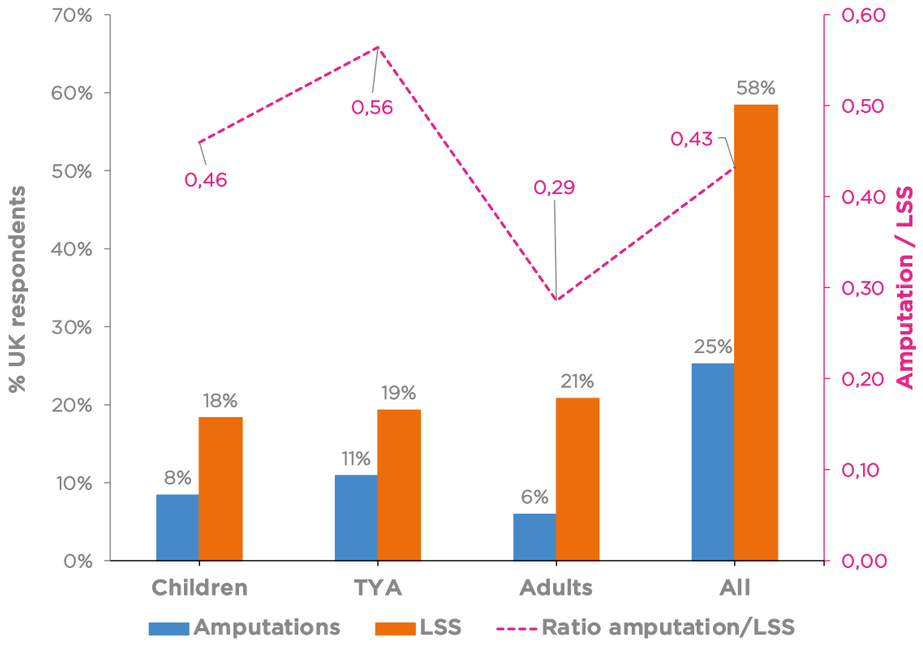
Amputation vs limb salvage surgery (LSS)

In general, 80-85% of osteosarcoma patients undergo surgery. Surgery is not an option when patients are too unwell, or when the tumour is in a location where it is too difficult to get to.

For those who undergo surgery, some receive limb salvage surgery (LSS). Other patients receive amputations or other complex surgeries. The decision to amputate or limb-salvage depends upon the size and extent of the tumour, whether nerves or blood vessels are involved by the tumour, i.e. whether a functional limb is achievable, and how tumours respond to chemo - radiotherapy.

For chondrosarcoma patients, for whom chemotherapy is not effective, the decision to amputate or limb-salvage is highly dependent on clear surgical margins and whether the preservation of a functional limb is possible. Therefore, improvements in surgical imaging techniques that allow surgeons to achieve better surgical margins not only improve survival, but also have an impact on the quality of life, by reducing the need for amputations.

UK Patient Survey amputation *vs* LSS



For very young bone sarcoma patients, inequalities in limb length is a very significant concern.

For these very young patients, the options other than amputation, are rotationplasty if, for example, the osteosarcoma or Ewing sarcoma occurs near the knee, or to use endoptostheses that lengthen as the patient grows.

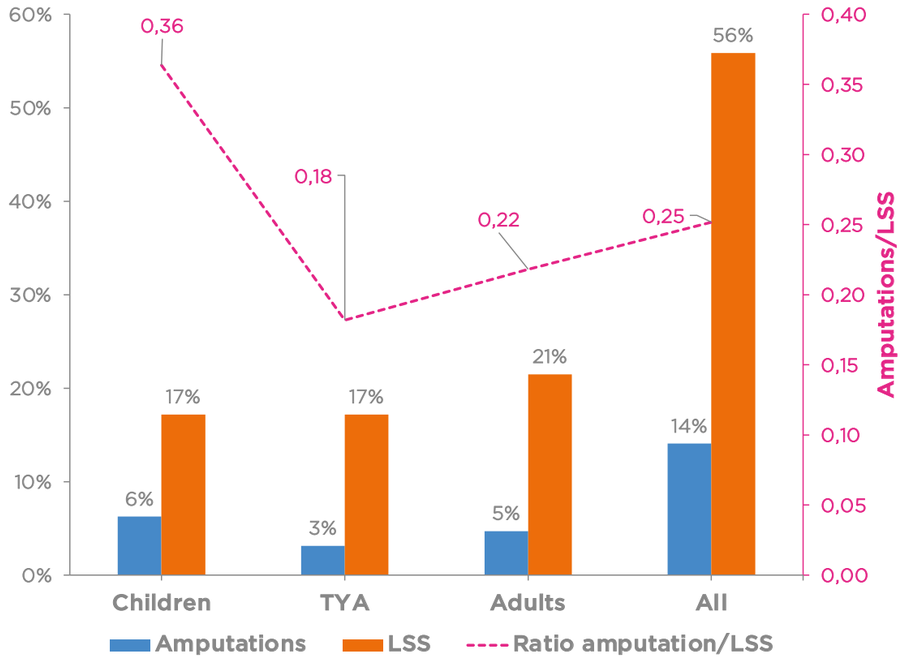
Rotationplasty is very effective and would not require revisions; however, it is a very specialised surgical procedure that is not widely performed.

Of the 202 respondents in the UK presenting with tumours in the extremities and the pelvis, 51 (25%) reported having had amputations and 118 (58%) had LSS. Only one patient underwent a rotationplasty.

By looking at the ratio of amputation / LSS, we can see that, for children (0-14) and TYAs (15-24), amputation was more prevalent than for adults, compared to LSS.

Outside the UK, eight rotationplasty surgeries were performed. Of the 256 patients with tumours in the extremities and the pelvis, 36 (14%) underwent amputations and 143 (56%) LSS. It seems that a higher proportion of patients in the UK undergo amputations. When we examined the ages of responders, a different pattern of practice outside the UK appeared in comparison to the UK. Still more children receive amputations than adults, but far less teenagers and young adults.

Outside the UK Patient Survey amputation *vs* LSS



Conclusion

The 2020 Patient Survey has resulted in a comprehensive evidence base to assess the current time and route to diagnosis for primary bone cancer patients in the UK. This has allowed us to set out a series of key findings and proposals to make improvements.

These results have highlighted the variety of symptoms that primary bone cancer patients present with to healthcare professionals, which often intensify with time. These symptoms differ across primary bone cancer types, the anatomical location of the tumour and the age of the patient.

The current NICE guidelines for the diagnosis of bone sarcomas have very little detail on presenting symptoms.

This breadth of presenting symptoms coupled with the rarity of primary bone cancers, with only 560 cases in the UK per year, make it particularly difficult to make accurate and timely diagnoses.

At present, the majority of patients initially report symptoms to their GP. The route to a specialist Bone Cancer Centre may involve a variety of different healthcare professionals and multiple attendances. This emphasises the importance of targeting a programme of education towards GPs. Children are more often referred from A&E to a specialist Bone Cancer Centre rather than from their GP, which indicates that any educational tool should highlight key differences amongst different age groups.

Patients often experience several issues with imaging, with 44% requiring more than 1 X-ray before the patient is referred, which highlights the importance of developing a programme of education targeted towards radiologists. This may be, in part, due to a high number of patients experiencing referred pain. 32% of all patients that experienced bone pain had pain at a separate anatomical location to where the tumour was later diagnosed. These findings emphasise the importance of trained radiologists, who are aware of the signs and symptoms of primary bone cancer. Any educational materials should reinforce the message that expertise from one of the specialist Bone Cancer Centres can be sought when interpreting imaging.

A quarter of all UK patients visit a physiotherapist at least once, with half of these patients visiting at least 4 times. These findings suggest that physiotherapists are a key profession, with the chance to make a positive impact on time to diagnosis and require the development of a programme of education.

1/3 OF ALL GP CONSULTATIONS ARE FOR MUSCULOSKELETAL DISORDERS

GPs WILL PROBABLY ONLY SEE 1 OR 2 CASES OF PRIMARY BONE CANCER IN THEIR CAREER

The capture and collation of the broad variety of symptoms has revealed the importance of looking at all the presenting symptoms collectively and not in isolation. Many symptoms of primary bone cancers are vague and can be mistaken for less serious conditions. However, patients rarely experience just one of these. In fact, they often experience bone pain in combination with issues relating to mobility, the presence of a lump and fatigue or weight loss. The combination of several of these symptoms is key to identifying primary bone cancers.

Many patients, residing both in and outside the UK, face multiple misdiagnoses before they are given an accurate diagnosis. Multiple missed opportunities for referral are wasteful of precious time for patients and often lead to inappropriate referrals to hospital consultants of other specialities, which is also wasteful of healthcare resources. Multiple misdiagnoses are also linked to a longer time to diagnosis and our data has demonstrated that the more alternative diagnoses given increase the likelihood that the patient will have metastatic disease at diagnosis.

Our survey results have suggested that patients make repeat visits to healthcare professionals, particularly GPs. This suggests that any education programme aimed at GPs should cover advice on safety netting patients. Safety netting measures may need implementing for patients making repeat visits to A&E, particularly for children that present at A&E more than once. Safety netting measures, such as children presenting more than once with pain or any other symptoms of primary bone cancer being seen by a consultant before being discharged or being automatically referred to a fracture clinic, may be worth exploring.

A timely diagnosis hinges on two factors; the patient reporting symptoms quickly and effectively (patient interval) and the healthcare professionals recognising these symptoms and making timely and accurate onward referrals (diagnostic interval).

Our results have identified differences in these two intervals amongst patients diagnosed in and outside of the UK. While UK patients report symptoms in a timelier fashion, they may face a lengthier time to diagnosis.

There is limited data in the literature, assessing the impact of delayed diagnosis on survival. Our data suggests that, in the UK, a diagnostic interval of six months or less can reduce the likelihood of the patient having metastatic disease at diagnosis, with the greatest reduction seen if diagnosis is within 1 month or less. These findings remain true when cases of osteosarcoma and Ewing sarcoma, the more aggressive forms of primary bone cancer, are isolated. Although striking, we acknowledge that the stage of disease at diagnosis does not fully reflect the eventual outcomes of patients[13]. Our data has not allowed the assessment of delayed diagnosis on overall survival and quality of life of patients due to the high numbers of respondents still receiving or just finishing treatment and it does not take in to account the biology of the tumours. However, we feel it has provided sufficient evidence to warrant further investigation through future clinical studies.

OUR AIM IS TO EVENTUALLY **REDUCE TIME TO DIAGNOSIS TO** 1 MONTH OR LESS **FOR ALL PATIENTS**

Ultimately our aim is to reduce time to diagnosis to 1 month or less for all patients, however, given the current average is over 7 months, we understand this will be a long-term ambition.

The importance of both the patient and diagnostic intervals emphasises the significance of raising awareness, not only amongst healthcare professionals but also amongst the public.

A precedent for the improvement in early diagnoses through a long-term awareness campaign targeted at healthcare professionals, has been set by the HeadSmart campaign. This campaign, a joint venture by the Children's Brain Tumour Research Centre, the Royal College of Paediatrics and Child Health and The Brain Tumour Charity was established in 2007 and has reduced the time to diagnosis for childhood brain tumours from 14.4 weeks to 6.7 weeks. These tumours, like primary bone tumours, are extremely rare, with 450 cases diagnosed per year in the UK.

Our findings suggest that there are significant gaps in knowledge amongst a wide range of healthcare professionals and have identified GPs, physiotherapists, radiologists, A&E doctors, medical students and dentists as key healthcare professionals. The 2020 Patient Survey has provided a comprehensive evidence base on which to focus our awareness objectives.

From the findings of this research

We will:

- Assemble an expert task force to develop training resources and peer-to-peer training opportunities to educate key healthcare professionals.
- Produce and nationally circulate bespoke educational tools tailored to each specialism, enabling each to recognise presenting symptoms and understand onward referral pathways.
- Launch public and healthcare professional-targeted campaigns to increase awareness and engagement with our new education resources.

We urge:

- Healthcare professionals to read this report and engage with the educational tools we will produce and make available.
- GPs and other healthcare professionals to remember it is the combination of several potentially vague symptoms that can identify primary bone cancer as a differential diagnosis and lead to a timely referral.
- Healthcare professionals to aim for a diagnosis to be made within 1 month or less for all suspected primary bone cancer cases.
- Referral of patients with continued pain or other key symptoms, even with a clear X-ray.

We recommend:

- These findings are used alongside the current NICE guidelines and to inform future versions.
- That a clinical study is undertaken to understand the reasons for, and the consequences of, delayed diagnosis.

To find out more about the progress we are making, please visit

bcrt.org.uk/awareness

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Appendix

Data tables

Relationship to the patient

Relationship to the patient	Responses	% Responses
Current patient	199	26.9%
Former patient	178	24.1%
Parent of a patient	284	38.4%
A friend or other family member of a patient	76	10.3%
Blank	2	0.3%
Total	**739**	**100.0%**

Residence at time of diagnosis

Residence at time of diagnosis	Responses	% Responses
UK	312	42.2%
Outside the UK	426	57.6%
Blank	1	0.1%
Total	**739**	**100.0%**

Sex

Sex	UK	Outside the UK	Blank	All	% UK	% Outside the UK	% All respondents
Male	129	188		317	41.3%	44.1%	42.9%
Female	182	236		418	58.3%	55.4%	56.6%
Prefer not to say		1		1	0.0%	0.2%	0.1%
Blank	1	1	1	3	0.3%	0.2%	0.4%
Total	**312**	**426**	**1**	**739**	**100.0%**	**100.0%**	**100.0%**

Age at diagnosis

Individual ages

Age at diagnosis	UK	Outside the UK	All	Age at diagnosis	UK	Outside the UK	All
1	1	2	3	**42**	5	3	8
2	0	1	1	**43**	2	8	10
3	0	3	3	**44**	1	5	6
4	3	4	7	**45**	1	6	7
5	3	8	11	**46**	2	4	6
6	1	7	8	**47**	3	3	6
7	7	5	12	**48**	6	1	7
8	8	6	14	**49**	2	5	7
9	6	8	14	**50**	6	2	8
10	7	14	21	**51**	3	3	6
11	13	14	27	**52**	3	2	5
12	19	11	30	**53**	2	5	7
13	15	17	32	**54**	1	3	4
14	12	17	29	**55**	5	4	9
15	17	22	39	**56**	0	2	2
16	16	22	38	**57**	3	5	8
17	13	23	36	**58**	2	2	4
18	11	10	21	**59**	4	0	4
19	5	14	19	**60**	3	2	5
20	5	6	11	**61**	1	0	1
21	3	10	13	**62**	1	1	2
22	10	15	25	**63**	1	2	3
23	3	2	5	**64**	4	0	4
24	6	8	14	**65**	0	3	3
25	1	4	5	**66**	0	1	1
26	5	5	10	**67**	1	2	3
27	4	13	17	**68**	4	1	5
28	4	6	10	**69**	0	0	0
29	5	7	12	**70**	0	2	2
30	8	5	13	**71**	0	0	0
31	3	4	7	**72**	0	0	0
32	2	6	8	**73**	0	0	0
33	3	5	8	**74**	0	0	0
34	2	8	10	**75**	0	0	0
35	3	5	8	**76**	0	0	0
36	4	6	10	**77**	0	0	0
37	4	5	9	**78**	0	0	0
38	3	3	6	**79**	0	1	1
39	2	7	9	**80**	0		0
40	3	7	10	**81**	1		1
41	4	3	7	**Blank**	2		2
				Total responses	**313**	**426**	**739**

Five-year age groups

5-Year age group	Number of respondents UK	Number of respondents outside the UK	Blank	All respondents
0-4	4	10		14
5-9	25	34		59
10-14	65	72		137
15-19	63	93		156
20-24	27	41		68

5-Year age group	Number of respondents UK	Number of respondents outside the UK	Blank	All respondents
25-29	19	34		53
30-34	18	28		46
35-39	16	26		42
40-44	15	26		41
45-49	14	19		33
50-54	15	15		30
55-59	14	13		27
60-64	10	5		15
65-69	5	7		12
70-74		2		2
75-79		1		1
80+	1			1
Blank	1		1	2
Total	**312**	**426**	**1**	**739**

Year of diagnosis

Year of diagnosis	UK	Outside the UK	UK + outside the UK	Residency not declared	All	Year of diagnosis	UK	Outside the UK	UK + outside the UK	Residency not declared	All
1968	1	0	1	0	1	**1995**	0	1	1	0	1
1969	0	0	0	0	0	**1996**	1	0	1	0	1
1970	1	0	1	0	1	**1997**	2	1	3	0	3
1971	0	0	0	0	0	**1998**	4	2	6	0	6
1972	0	0	0	0	0	**1999**	3	5	8	0	8
1973	0	0	0	0	0	**2000**	4	0	4	0	4
1974	0	0	0	0	0	**2001**	2	2	4	0	4
1975	0	0	0	0	0	**2002**	3	2	5	0	5
1976	0	0	0	0	0	**2003**	2	2	4	0	4
1977	1	0	1	0	1	**2004**	3	3	6	0	6
1978	1	0	1	0	1	**2005**	4	2	6	0	6
1979	0	0	0	0	0	**2006**	5	3	8	0	8
1980	5	0	5	0	5	**2007**	6	3	9	0	9
1981	2	0	2	0	2	**2008**	7	10	17	0	17
1982	0	0	0	0	0	**2009**	12	7	19	0	19
1983	1	0	1	0	1	**2010**	8	0	8	0	8
1984	1	1	2	0	2	**2011**	5	4	9	0	9
1985	1	0	1	0	1	**2012**	9	5	14	0	14
1986	1	1	2	0	2	**2013**	11	13	24	0	24
1987	0	1	1	0	1	**2014**	21	9	30	0	30
1988	1	0	1	0	1	**2015**	19	26	45	0	45
1989	1	4	5	0	5	**2016**	14	28	42	0	42
1990	0	1	1	0	1	**2017**	25	32	57	1	58
1991	2	0	2	0	2	**2018**	27	59	86	0	86
1992	2	2	4	0	4	**2019**	45	84	129	0	129
1993	2	3	5	0	5	**2020**	12	49	61	0	61
1994	1	0	1	0	1	**Blank**	34	61	95	0	95
						Total					**739**

Type of primary bone cancer and residence at diagnosis

Primary bone cancer/tumour	UK	Outside the UK	Not declared	All	% UK	% Outside the UK	% Not declared	% All
Adamantinoma	1	5		6	0.3%	1.2%	0.0%	0.8%
Ameloblastoma	9	17		26	2.9%	4.0%	0.0%	3.5%
Angiosarcoma of the Bone	2	1		3	0.6%	0.2%	0.0%	0.4%
Chondrosarcoma	30	69		99	9.6%	16.2%	0.0%	13.4%
Chordoma	24	4		28	7.7%	0.9%	0.0%	3.8%
Ewing sarcoma	81	96	1	178	26.0%	22.5%	100.0%	24.1%
Giant Cell Tumour of the Bone	22	39		61	7.1%	9.2%	0.0%	8.3%
Osteosarcoma	101	131		232	32.4%	30.8%	0.0%	31.4%
Spindle Cell Sarcoma of the Bone	6	3		9	1.9%	0.7%	0.0%	1.2%
Other	36	61		97	11.5%	14.3%	0.0%	13.1%
Total	**312**	**426**	**1**	**739**	**100.0%**	**100.0%**	**100.0%**	**100.0%**

Type of primary bone cancer and 5-year age group at diagnosis

Primary bone cancer type by age

5 -Year age group	Angiosarcoma of the Bone	Adamantinoma	Spindle Cell Sarcoma of the Bone	Ameloblastoma	Chordoma	Giant Cell Tumour of the Bone	Chondrosarcoma	Ewing sarcoma	Osteosarcoma	Blank-Other	All types
0-4	1				1			9	2	1	14
5-9		1						27	22	9	59
10-14			1		1	1	1	43	76	15	138
15-19		2	1	3		7	9	54	63	16	155
20-24				3		7	7	24	19	8	68
25-29	1		1	4	1	8	11	8	11	8	53
30-34		1	2	3		10	8	4	10	8	46

5 -Year age group	Angiosarcoma of the Bone	Adamantinoma	Spindle Cell Sarcoma of the Bone	Ameloblastoma	Chordoma	Giant Cell Tumour of the Bone	Chondrosarcoma	Ewing sarcoma	Osteosarcoma	Blank-Other	All types
35-39		1		1	6	10	8	2	10	4	42
40-44		1		2	3	9	12	2	7	5	41
45-49	1		2	6	5	5	6	1	3	4	33
50-54			1	3	2	1	10		7	6	30
55-59			1		2	3	14	1	2	4	27
60-64					5		6	2		2	15
65-69				1	1		5			5	12
70-74							1			1	2
75-79							1				1
80+					1						1
Blanks								1		1	2
Total	**3**	**6**	**9**	**26**	**28**	**61**	**99**	**178**	**232**	**97**	**739**

Anatomical site of primary bone cancer grouped by ICD-10 site codes

ICD-10 code	Number of respondents for each ICD-10 code	% of ICD-10
Upper limbs (C40.0-C40.1)	64	9%
Lower limbs (C40.2-C40.3)	325	44%
Head (C41.0-C41.1)	63	9%
Vertebral column (C41.2)	31	4%
Ribs sternum and clavicle (C41.3)	55	7%
Pelvic bones (C41.4)	99	13%
Bone, overlapping and unspecified (C40.8-C40.9, C41.8-C41.9)	8	1%
Blanks answers	94	13%
Total	**739**	**100%**

Stage at diagnosis: local or metastatic disease

UK	Local	Metastatic	Total	% Local	% Metastatic	Unknown	Blank
Children (0-14)	56	26	82	68%	32%	3	9
TYA (15-24)	59	19	78	76%	24%	4	8
Adult (25+)	90	18	108	83%	17%	5	14
Unknown age							1
All ages	205	63	268	**76%**	**24%**	12	32

Outside the UK	Local	Metastatic	Total	% Local	% Metastatic	Unknown	Blank
Children (0-14)	64	33	97	66%	34%	4	15
TYA (15-24)	83	28	111	75%	25%	8	15
Adult (25+)	121	21	142	86%	15%	3	31
All ages	268	82	350	**77%**	**23%**	15	61

Patient interval males/females

Patient interval (months)	All	% All patient interval	Males	% Patient interval males	females	% Patient interval females
0-1	238	37%	102	38%	136	37%
1	103	16%	45	17%	58	16%
2	93	15%	44	16%	49	13%
3	66	10%	34	13%	32	9%
4	31	5%	9	3%	21	6%
5	11	2%	2	1%	9	2%
6	35	5%	14	5%	20	5%
7	3	0%	1	0%	2	1%
8	3	0%	1	0%	2	1%
9	2	0%	1	0%	1	0%
10	4	1%	1	0%	3	1%
11	0	0%	0	0%	0	0%
12	15	2%	5	2%	10	3%
13-18	11	2%	4	1%	7	2%
18-24	10	2%	2	1%	8	2%
>24	16	2%	4	1%	11	3%
Total	**641**	**100%**	**269**	**100%**	**369**	**100%**
≤1	341	**53%**	147	**55%**	194	**53%**
>1	300	**47%**	122	**45%**	175	**47%**

Diagnostic interval males/females

Diagnostic interval (months)	All	% Diagnostic interval all	Males	% Diagnostic interval males	Females	% Diagnostic interval females
0-1	190	30%	79	29%	110	30%
1	65	10%	30	11%	35	9%
2	69	11%	30	11%	39	11%
3	72	11%	32	12%	40	11%
4	35	5%	15	6%	20	5%
5	28	4%	13	5%	15	4%
6	48	7%	18	7%	30	8%
7	15	2%	9	3%	6	2%
8	15	2%	5	2%	10	3%
9	8	1%	4	1%	3	1%
10	9	1%	5	2%	4	1%
11	3	0%	1	0%	2	1%
12	15	2%	6	2%	9	2%
13-17	14	2%	5	2%	9	2%
18-23	19	3%	6	2%	12	3%
>24	39	6%	12	4%	27	7%
Total	**644**	**100%**	**270**	**100%**	**371**	**100%**
≤1 month	255	**40%**	109	**40%**	145	39%
>1 month	389	**60%**	161	**60%**	226	61%

UK / Outside the UK, not males / females

Patient interval (months)	All	% All Patient interval	UK	% Patient interval UK	Outside the UK	% Patient interval outside the UK
0-1	238	37%	117	42%	121	33%
1	103	16%	48	17%	55	15%
2	93	15%	36	13%	57	16%
3	66	10%	32	12%	34	9%
4	31	5%	3	1%	28	8%
5	11	2%	2	1%	9	2%
6	35	5%	15	5%	19	5%
7	3	0%	0	0%	3	1%
8	3	0%	1	0%	2	1%
9	2	0%	0	0%	2	1%
10	4	1%	2	1%	2	1%
11	0	0%	0	0%	0	0%
12	15	2%	6	2%	9	2%
13-18	11	2%	7	3%	4	1%
18-24	10	2%	4	1%	6	2%
>24	16	2%	4	1%	12	3%
Total	**641**	**100%**	**277**	**100%**	**363**	**100%**
≤1 month	341	**53%**	165	**60%**	176	**48%**
>1 month	300	**47%**	112	**40%**	187	**52%**

Diagnostic interval UK/outside the UK

Diagnostic interval (months)	All	% Diagnostic interval All	UK	% Diagnostic interval UK	Outside the UK	% Diagnostic interval outside UK
0-1	190	30%	52	19%	137	38%
1	65	10%	23	8%	42	12%
2	69	11%	34	12%	35	10%
3	72	11%	36	13%	36	10%
4	35	5%	13	5%	22	6%
5	28	4%	17	6%	11	3%
6	48	7%	28	10%	20	5%
7	15	2%	8	3%	7	2%
8	15	2%	10	4%	5	1%
9	8	1%	2	1%	6	2%
10	9	1%	6	2%	3	1%
11	3	0%	2	1%	1	0%
12	15	2%	9	3%	6	2%
13-17	14	2%	10	4%	4	1%
18-23	19	3%	12	4%	7	2%
>24	39	6%	17	6%	22	6%
Total	**644**	**100%**	**279**	**100%**	**364**	**100%**
≤1	255	**40%**	75	**27%**	179	**49%**
>1	389	**60%**	204	**73%**	185	**51%**

Patient and Diagnostic interval osteosarcoma patients UK

Months	Patient interval (n)	%		Months	Diagnostic interval (n)	%	
0-1	47	47%	**≤1 month**	**0-1**	28	28%	**≤1 month**
1	21	21%		**1**	9	9%	
2	10	10%	**>1 month**	**2**	16	16%	**>1 month**
3	10	10%		**3**	15	15%	
4	1	1%		**4**	5	5%	
5	0	0%		**5**	5	5%	
6	6	6%		**6**	9	9%	
7	0	0%		**7**	0	0%	
8	0	0%		**8**	1	1%	
9	0	0%		**9**	1	1%	
10	1	1%		**10**	1	1%	
11	0	0%		**11**	1	1%	
12	3	3%		**12**	2	2%	
13-17	0	0%		**13-17**	1	1%	
18-23	0	0%		**18-23**	1	1%	
>24	1	1%		**>24**	6	6%	
blank	1	1%		**blank**	0	0%	
Total	101	100%		**Total**	101	100%	

Patient and Diagnostic interval Ewing sarcoma patients UK

Months	Patient interval (n)	%		Months	Diagnostic interval (n)	%	
0-1	37	46%	**≤1 month**	**0-1**	13	16%	**≤1 month**
1	15	19%		**1**	6	7%	
2	12	15%	**>1 month**	**2**	6	7%	**>1 month**
3	9	11%		**3**	15	19%	
4	0	0%		**4**	3	4%	
5	1	1%		**5**	4	5%	
6	4	5%		**6**	8	10%	
7	0	0%		**7**	4	5%	
8	1	1%		**8**	1	1%	
9	0	0%		**9**	0	0%	
10	0	0%		**10**	2	2%	
11	1	1%		**11**	1	1%	
12	0	0%		**12**	4	5%	
13-17	0	0%		**13-17**	7	9%	
18-23	0	0%		**18-23**	5	6%	
>24	1	1%		**>24**	2	2%	
blank	0	0%		**blank**	0	0%	
Total	**81**	**100%**		**Total**	81	100%	

UK Total interval and stage at diagnosis			
TI (months)	**Local**	**Metastatic**	**Total diagnoses**
1	18	2	20
2	21	2	23
3	29	7	36
4	22	13	35
5	14	5	19
6	10	5	15
7	17	7	24
8	10	3	13
9	9	4	13
10	1	0	1
11	3	0	3
12	4	4	8
13 - 17	11	3	14
18 - 23	4	2	6
24 +	30	5	35

UK Total interval and % Metastatic / Local disease					
TI	**Local**	**Met**	**Local + Met**	**% Local**	**% Met**
1 month	18	2	20	90%	10%
1-2 months	39	4	43	91%	9%
1-3 months	68	11	79	86%	14%
1-4 months	90	24	114	79%	21%
1-5 months	104	29	133	78%	22%
1-6 months	114	34	148	77%	23%
1-7 months	131	41	172	76%	24%
1-8 months	141	44	185	76%	24%
1-9 months	150	48	198	76%	24%
1-10 months	151	48	199	76%	24%
1-11 months	154	48	202	76%	24%
1-12 months	158	52	210	75%	25%
1-17 months	169	55	224	75%	25%
1-23 months	173	57	230	75%	25%
1-24+ months	203	62	265	77%	23%

Outside the UK total interval and stage at diagnosis			
TI (months)	**Local**	**Met**	**Total Diagnoses**
1	43	7	50
2	30	8	38
3	35	10	45
4	27	11	38
5	22	6	28

TI (months)	Local	Met	Total Diagnoses
6	16	8	24
7	16	10	26
8	6	6	12
9	8	2	10
10	6	1	7
11	2	2	4
12	3	1	4
13 - 17	17	3	15
18 - 24	5	0	5
24 +	29	8	37

Outside the UK Total interval and % Metastatic/Local disease					
TI	**Local**	**Met**	**Local + Met**	**% Local**	**% Met**
1 month	43	7	50	86%	14%
1-2 months	73	15	88	83%	17%
1-3 months	108	25	133	81%	19%
1-4 months	135	36	171	79%	21%
1-5 months	157	42	199	79%	21%
1-6 months	173	50	223	78%	22%
1-7 months	189	60	249	76%	24%
1-8 months	195	66	261	75%	25%
1-9 months	203	68	271	75%	25%
1-10 months	209	69	278	75%	25%
1-11 months	211	71	282	75%	25%
1-12 months	214	72	286	75%	25%
1-17 months	231	75	306	75%	25%
1-23 months	236	75	311	76%	24%
1-24+ months	265	83	348	76%	24%

A&E as first visit by primary bone cancer/tumour and age	Children	TYAs	Adults
Adamantinoma			
Ameloblastoma			
Angiosarcoma of the Bone			
Chondrosarcoma		1 (10%)	3 (33%)
Chordoma			1(11%)
Ewing sarcoma	4 (33%)	6 (60%)	
Giant Cell Tumour of the Bone			3 (33%)
Osteosarcoma	8 (67%)	3 (30%)	1 (11%)
Spindle Cell Sarcoma of the Bone			1 (11%)

First visit to a healthcare professional

	GP NHS	A&E	Physiotherapist	Dentist	Hospital appointment	Other	Blank
Adamantinoma	1						
Ameloblastoma	4			5			
Angiosarcoma of the Bone	1				1		
Chondrosarcoma	22	4	1	1	1	1	
Chordoma	19	1			3	1	
Ewing sarcoma	66	10		1	2	2	
Giant Cell Tumour of the Bone	17	3	1			1	
Osteosarcoma	74	12	4	3	5	2	1
Spindle Cell Sarcoma of the Bone	4	1			1		
Other	3		1				32
All types	**211**	**31**	**7**	**10**	**13**	**7**	**33**
Total 279 + 33 =312	279						
Percentage (out of 279)	**76%**	**11%**	**3%**	**4%**	**5%**	**3%**	

Number of visits to a healthcare professional

Number of visits to a healthcare professional UK	Number of patients	% of UK patients (not including the 43 non-respondents n = 269)
blank	43	
1	9	3%
2	27	10%
3	27	10%
4	30	11%
5	26	10%
6	24	9%
7	21	8%
8	18	7%
9	8	3%
10	11	4%
11-15	36	13%
16-20	18	7%
21-25	7	3%
Over 25	7	3%
Total	269	100%

Number of visits to a healthcare professional outside the UK	Number of patients	% of outside UK patients (not including the 112 non respondents n = 314)
Blank	112	
1	32	10%
2	46	15%
3	45	14%
4	46	15%
5	36	11%
6	22	7%
7	20	6%
8	14	4%
9	5	2%
10	6	2%
11-15	18	6%
16-20	7	2%
21-25	4	1%
Over 25	13	4%
	426	
	314	100%

Number of visits to each healthcare professional before receiving a diagnosis

Number of visits UK	GP - NHS	GP - private	Physiotherapist	Orthopaedic / fracture clinic	A&E	Chiropractor	Dentist	Optician	Private healthcare consultant	Other hospital consultant	X-ray / imaging department	Other	Total
1	43	6	16	16	67	4	7	6	15	36	93	5	**314**
2	52	3	14	12	18	1	1	0	10	20	38	3	**172**
3	42	2	7	1	7	2	2	0	4	8	15	1	**91**
4	32	0	7	1	2	2	2	0	1	6	12	1	**66**
5	8	0	7	1	2	1	1	0	1	1	3	0	**25**
6	20	0	8	2	1	2	0	0	1	1	2	0	**37**
7	5	0	3	0	1	1	0	0	0	1	1	0	**12**
8	9	0	4	0	1	0	0	0	0	2	0	0	**16**
9	1	0	0	0	0	0	0	0	0	0	0	0	**1**
10	6	0	4	1	2	0	0	0	0	0	1	0	**14**
11	0	0	0	0	0	0	0	0	0	0	0	0	**0**
12	5	0	1	0	0	1	0	0	0	0	0	0	**7**
13	1	0	0	0	0	0	0	0	0	0	0	0	**1**
14	0	0	0	0	0	0	0	0	0	0	0	0	**0**
15	1	0	0	0	1	0	0	0	0	0	0	0	**2**
16	0	0	0	0	0	0	0	0	0	0	0	0	**0**
17	0	0	0	0	0	0	0	0	0	0	0	0	**0**

Number of visits UK	GP - NHS	GP - private	Physiotherapist	Orthopaedic / fracture clinic	A&E	Chiropractor	Dentist	Optician	Private healthcare consultant	Other hospital consultant	X-ray / imaging department	Other	Total
18	0	0	0	0	0	0	0	0	0	0	0	0	**0**
19	0	0	0	0	0	0	0	0	0	0	0	0	**0**
20	2	0	0	0	0	0	0	0	0	0	0	0	**2**
21	1	0	0	0	0	0	0	0	0	0	0	0	**1**
22	0	0	0	0	0	0	0	0	0	0	0	0	**0**
23	0	0	0	0	0	0	0	0	0	0	0	0	**0**
24	0	0	0	0	0	0	0	0	0	0	0	0	**0**
25	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Over 25	1	0	2	1	0	1	0	0	0	0	0	2	**7**
total	**229**	**11**	**73**	**35**	**102**	**15**	**13**	**6**	**32**	**75**	**165**	**12**	**768**
UK n = 312	**UK visits n = 768**												

Number of visits Outside the UK	GP - NHS	GP - private	Physiotherapist	Orthopaedic / fracture clinic	A&E	Chiropractor	Dentist	Optician	Private healthcare consultant	Other hospital consultant	X-ray / imaging department	Other	Total
1	26	58	6	54	2	5	8	0	18	25	82	19	**303**
2	17	39	6	27	8	1	4	0	11	19	70	15	**217**
3	10	27	7	15	2	5	1	0	6	8	27	8	**116**
4	2	11	3	6	0	5	2	0	1	3	7	1	**41**
5	1	2	3	4	0	2	0	1	0	3	10	2	**28**
6	5	5	4	2	0	5	1	0	1	0	8	1	**32**
7	1	0	0	0	0	0	1	0	0	0	0	1	**3**
8	0	2	4	0	0	4	1	0	1	1	0	0	**13**
9	0	1	0	2	0	0	0	0	0	0	0	0	**3**
10	1	1	4	1	0	0	0	0	0	0	4	0	**11**
11	0	0	0	0	0	0	0	0	0	0	0	0	**0**
12	1	0	2	0	0	0	0	0	0	0	0	0	**3**
13	0	0	0	0	0	0	0	0	0	0	0	0	**0**
14	0	0	2	0	0	0	0	0	0	0	0	0	**2**
15	0	0	0	2	0	1	0	0	0	0	0	1	**4**
16	0	0	0	0	0	0	0	0	0	0	0	0	**0**
17	0	0	0	0	0	0	0	0	0	0	0	0	**0**
18	0	0	0	0	0	0	0	0	0	0	0	0	**0**
19	0	0	0	0	0	0	0	0	0	0	0	0	**0**
20	1	0	2	0	0	2	0	0	0	0	0	0	**5**

Number of visits Outside the UK	GP - NHS	GP - private	Physiotherapist	Orthopaedic / fracture clinic	A&E	Chiropractor	Dentist	Optician	Private healthcare consultant	Other hospital consultant	X-ray / imaging department	Other	Total
21	0	0	0	0	0	0	0	0	0	0	0	0	**0**
22	0	0	0	0	0	0	0	0	0	0	0	0	**0**
23	0	0	0	0	0	0	0	0	0	0	0	0	**0**
24	0	0	0	0	0	0	0	0	0	0	0	0	**0**
25	0	0	1	0	0	0	0	0	0	0	0	0	**1**
Over 25	0	1	4	0	0	3	0	0	0	0	0	1	**9**
total	**65**	**147**	**48**	**113**	**12**	**33**	**18**	**1**	**38**	**59**	**208**	**49**	**791**
Outside UK n = 426	**Outside UK visits n = 791**												

Percentage of patients visiting each healthcare professional

UK Number of visits to each healthcare professional

Number of visits	UK GP	UK GP - private	UK GP NHS + private	UK Physiotherapist	UK Orthopaedic / fracture clinic	UK A&E	UK Chiropractor	UK Dentist	UK Optician	UK Private healthcare consultant	UK Other hospital consultant	UK X-ray / imaging department	UK Other
1	43	6	49	16	16	67	4	7	6	15	36	93	5
2	52	3	55	14	12	18	1	1	0	10	20	38	3
3	42	2	44	7	1	7	2	2	0	4	8	15	1
4	32	0	32	7	1	2	2	2	0	1	6	12	1
5	8	0	8	7	1	2	1	1	0	1	1	3	0
6	20	0	20	8	2	1	2	0	0	1	1	2	0
7	5	0	5	3	0	1	1	0	0	0	1	1	0
8	9	0	9	4	0	1	0	0	0	0	2	0	0
9	1	0	1	0	0	0	0	0	0	0	0	0	0
10	6	0	6	4	1	2	0	0	0	0	0	1	0
11	0	0	0	0	0	0	0	0	0	0	0	0	0
12	5	0	5	1	0	0	1	0	0	0	0	0	0
13	1	0	1	0	0	0	0	0	0	0	0	0	0
14	0	0	0	0	0	0	0	0	0	0	0	0	0
15	1	0	1	0	0	1	0	0	0	0	0	0	0
16	0	0	0	0	0	0	0	0	0	0	0	0	0
17	0	0	0	0	0	0	0	0	0	0	0	0	0
18	0	0	0	0	0	0	0	0	0	0	0	0	0
19	0	0	0	0	0	0	0	0	0	0	0	0	0
20	2	0	2	0	0	0	0	0	0	0	0	0	0

Number of visits	UK GP	UK GP - private	UK GP NHS + private	UK Physiotherapist	UK Orthopaedic / fracture clinic	UK A&E	UK Chiropractor	UK Dentist	UK Optician	UK Private healthcare consultant	UK Other hospital consultant	UK X-ray / imaging department	UK Other
21	1	0	1	0	0	0	0	0	0	0	0	0	0
22	0	0	0	0	0	0	0	0	0	0	0	0	0
23	0	0	0	0	0	0	0	0	0	0	0	0	0
24	0	0	0	0	0	0	0	0	0	0	0	0	0
25	1	0	1	2	1	0	1	0	0	0	0	0	2

UK % of visits to each healthcare professional

Number of visits	% UK GP	% UK GP - private	% UK GP NHS + Private	% UK Physiotherapist	% UK Orthopaedic / Fracture clinic	% UK A&E	%UK Chiropractor	%UK Dentist	% UK Optician	% UK Private healthcare consultant	% UK Other hospital consultant	% UK X-ray / imaging department	% UK Other
1	13.8%	1.9%	15.7%	5.1%	5.1%	21.5%	1.3%	2.2%	1.9%	4.8%	11.5%	29.8%	1.6%
2	16.7%	1.0%	17.6%	4.5%	3.8%	5.8%	0.3%	0.3%	0.0%	3.2%	6.4%	12.2%	1.0%
3	13.5%	0.6%	14.1%	2.2%	0.3%	2.2%	0.6%	0.6%	0.0%	1.3%	2.6%	4.8%	0.3%
4	10.3%	0.0%	10.3%	2.2%	0.3%	0.6%	0.6%	0.6%	0.0%	0.3%	1.9%	3.8%	0.3%
5	2.6%	0.0%	2.6%	2.2%	0.3%	0.6%	0.3%	0.3%	0.0%	0.3%	0.3%	1.0%	0.0%
6	6.4%	0.0%	6.4%	2.6%	0.6%	0.3%	0.6%	0.0%	0.0%	0.3%	0.3%	0.6%	0.0%
7	1.6%	0.0%	1.6%	1.0%	0.0%	0.3%	0.3%	0.0%	0.0%	0.0%	0.3%	0.3%	0.0%
8	2.9%	0.0%	2.9%	1.3%	0.0%	0.3%	0.0%	0.0%	0.0%	0.0%	0.6%	0.0%	0.0%
9	0.3%	0.0%	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
10	1.9%	0.0%	1.9%	1.3%	0.3%	0.6%	0.0%	0.0%	0.0%	0.0%	0.0%	0.3%	0.0%
11	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
12	1.6%	0.0%	1.6%	0.3%	0.0%	0.0%	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
13	0.3%	0.0%	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
14	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
15	0.3%	0.0%	0.3%	0.0%	0.0%	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
16	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
17	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
18	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
19	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
20	0.6%	0.0%	0.6%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
21	0.3%	0.0%	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
22	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
23	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
24	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
25	0.3%	0.0%	0.3%	0.6%	0.3%	0.0%	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.6%

Outside the UK Number of visits to each healthcare professional

Outside UK number of visits	GP - public	GP - private-	GP public + private	Physiotherapist	Orthopaedic / Fracture clinic	A&E	Chiropractor	Dentist	Optician	Private healthcare consultant	Other hospital consultant	X-ray / imaging department	Other
1	27	59	86	10	55	2	5	8	0	18	25	86	19
2	18	39	57	8	27	8	3	4	0	11	19	70	15
3	10	27	37	7	15	2	5	1	0	6	8	27	8
4	2	11	13	3	6	0	5	2	0	1	3	7	1
5	1	2	3	3	4	0	2	0	1	0	3	10	2
6	5	5	10	4	2	0	5	1	0	1	0	8	1
7	1	0	1	0	0	0	0	1	0	0	0	0	1
8	0	2	2	4	0	0	4	1	0	1	1	0	0
9	0	1	1	0	2	0	0	0	0	0	0	0	0
10	0	0	0	0	0	0	0	0	0	0	0	0	0
11	0	0	0	0	0	0	0	0	0	0	0	0	0
12	1	0	1	2	0	0	0	0	0	0	0	0	0
13	0	0	0	0	0	0	0	0	0	0	0	0	0
14	0	0	0	2	0	0	0	0	0	0	0	0	0
15	0	0	0	0	2	0	1	0	0	0	0	0	1
16	0	0	0	0	0	0	0	0	0	0	0	0	0
17	0	0	0	0	0	0	0	0	0	0	0	0	0
18	0	0	0	0	0	0	0	0	0	0	0	0	0
19	0	0	0	0	0	0	0	0	0	0	0	0	0
20	0	0	0	0	0	0	0	0	0	0	0	0	0
21	0	0	0	0	0	0	0	0	0	0	0	0	0
22	0	0	0	0	0	0	0	0	0	0	0	0	0
23	0	0	0	0	0	0	0	0	0	0	0	0	0
24	0	0	0	0	0	0	0	0	0	0	0	0	0
25	0	1	1	5	0	0	3	0	0	0	0	0	1

Outside the UK % of visits to each healthcare professional

Outside UK number of visits	% Outside UK GP - public	% Outside UK GP - private	%Outside UK GP public + Private	% Outside UK physiotherapist	% Outside UK Orthopaedic / fracture clinic	% Outside UK A&E	% Outside UK Chiropractor	% Outside UK Dentist	% Outside UK Optician	% Outside UK Private healthcare consultant	% Outside UK Other hospital consultant	% Outside UK X-ray / imaging department	% Outside UK Other
1	6%	14%	20%	2%	13%	0%	1%	2%	0%	4%	6%	20%	4%
2	4%	9%	13%	2%	6%	2%	1%	1%	0%	3%	4%	16%	4%

Outside UK number of visits	% Outside UK GP - public	% Outside UK GP - private	%Outside UK GP public + Private	% Outside UK physiotherapist	% Outside UK Orthopaedic / fracture clinic	% Outside UK A&E	% Outside UK Chiropractor	% Outside UK Dentist	% Outside UK Optician	% Outside UK Private healthcare consultant	% Outside UK Other hospital consultant	% Outside UK X-ray / imaging department	% Outside UK Other
3	2%	6%	9%	2%	4%	0%	1%	0%	0%	1%	2%	6%	2%
4	0%	3%	3%	1%	1%	0%	1%	0%	0%	0%	1%	2%	0%
5	0%	0%	1%	1%	1%	0%	0%	0%	0%	0%	1%	2%	0%
6	1%	1%	2%	1%	0%	0%	1%	0%	0%	0%	0%	2%	0%
7	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
8	0%	0%	0%	1%	0%	0%	1%	0%	0%	0%	0%	0%	0%
9	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
10	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
11	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
12	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
13	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
14	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
15	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
16	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
17	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
18	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
19	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
20	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
21	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
22	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
23	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
24	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
25	0%	0%	0%	1%	0%	0%	1%	0%	0%	0%	0%	0%	0%

Referral routes UK data by age

Who made the referral? UK data										
5-year group	**GP-NHS**	**GP-private**	**A&E**	**Fracture clinic**	**Physiotherapist**	**X-ray**	**Orthopaedic consultant (including private)**	**Dentist/Dental hospital**	**Other hospital consultant**	**Other**
0-4			1	1					1	
5-9	2		6	4		4			4	2

5-year group	GP-NHS	GP-private	A&E	Fracture clinic	Physiotherapist	X-ray	Orthopaedic consultant (including private)	Dentist/Dental hospital	Other hospital consultant	Other
10-14	7		11	9		12			15	5
15-19	4	2	5	11	2	6	3		15	8
20-24	9		2	1	1	2		1	6	4
25-29	1	1	1	4		1		1	9	
30-34	1	2	2	2		1		1	7	1
35-39	2		2	3	1	4			3	0
40-44	2	2	2	2		1		1	3	1
45-49	1	1	1	2					5	3
50-54	2	2	1	2	1			1	3	1
55-59	1	1		4					4	3
60-64	3						1		2	2
65-69	1									
70-74										
75-79										
80+		1								
blanks	33									
Total	36	12	34	45	5	31	4	5	77	30
All cases UK n=312	279 (no blanks)	33 blanks								

Who made the referral? %

5-year group	% GP-NHS	% GP-private	% A&E	% Fracture clinic	% Physio	% x-ray	%Orthopaedic consultant (including private)	%Dentist/Dental hospital	%Other hospital consultant	% Other
0-4	0.0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
5-9	0.7%	0%	2%	1%	0%	1%	0%	0%	1%	1%
10-14	2.5%	0%	4%	3%	0%	4%	0%	0%	5%	2%
15-19	1.4%	1%	2%	4%	1%	2%	1%	0%	5%	3%
20-24	3.2%	0%	1%	0%	0%	1%	0%	0%	2%	1%
25-29	0.4%	0%	0%	1%	0%	0%	0%	0%	3%	0%
30-34	0.4%	1%	1%	1%	0%	0%	0%	0%	3%	0%
35-39	0.7%	0%	1%	1%	0%	1%	0%	0%	1%	0%

5-year group	% GP-NHS	% GP-private	% A&E	% Fracture clinic	% Physio	% x-ray	%Orthopaedic consultant (including private)	%Dentist/Dental hospital	%Other hospital consultant	% Other
40-44	0.7%	1%	1%	1%	0%	0%	0%	0%	1%	0%
45-49	0.4%	0%	0%	1%	0%	0%	0%	0%	2%	1%
50-54	0.7%	1%	0%	1%	0%	0%	0%	0%	1%	0%
55-59	0.4%	0%	0%	1%	0%	0%	0%	0%	1%	1%
60-64	1.1%	0%	0%	0%	0%	0%	0%	0%	1%	1%
65-69	0.4%	0%	0%	0%	0%	0%	0%	0%	0%	0%
70-74	0.0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
75-79	0.0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
80+	0.0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
blanks	0.11828	0	0	0%	0	0	0	0%	0%	0%
Total	12.9%	4%	12%	16%	2%	11%	1%	2%	28%	11%
All cases UK n=312		33 blanks								

Referral respondents (UK) age groups			
Children	**TYAs**	**Adults**	**Blank**
84	82	113	1
30.10%	28.80%	40.70%	0.30%

Who made the referral? By age groups UK										
	GP-NHS	GP-private	A&E	Fracture clinic	Physiotherapist	X-ray department	Orthopaedic consultant (including private)	Dentist/Dental hospital	Other Hospital consultant	Other
Children	9	0	18	14	0	16	0	0	20	7
TYAs	13	2	7	12	3	8	3	1	21	12
Adults	14	10	9	19	2	7	1	4	36	11
	% GP NHS	% GP-private	% A&E	% Fracture Clinic	% Physiotherapist	% X-ray department	%Orthopaedic consultant (including private)	%Dentist/Dental hospital	%Other hospital consultant	% Other
Children	11%	0%	21%	17%	0%	19%	0%	0%	24%	8%
TYAs	16%	2%	9%	15%	4%	10%	4%	1%	26%	15%
Adults	12%	9%	8%	17%	2%	6%	1%	4%	32%	10%

Referral by A&E UK data – comparison of where patients initially reported symptoms

	Referred by A&E	Number initially attended GP	Number initially attended A&E
Total	34	28	6
Children (0-14)	18	12	6
TYAs (15-24)	7	6	1
Adults (25+)	9	9	0

Referral routes UK data by type of primary bone cancer/tumour

Primary bone cancer/tumour type - referral breakdown UK only							
Number of referrals							
	GP	A&E	X-ray and imaging department	Orthopaedic and fracture clinic	Other hospital consultant	Other healthcare professional	Total referrals
Chondrosarcoma	8	2	0	6	13	0	29
Osteosarcoma	15	17	14	22	22	5	95
Ewing sarcoma	9	11	12	13	31	2	78
Chordoma	9	2	2	2	8	0	23
Adamantinoma	0	0	1		0	0	1
Spindle Cell Sarcoma of the Bone	2	0	1		3	0	6
Angiosarcoma of the Bone	0	0			2	0	2
Giant Cell Tumour of Bone	4	2		6	6	2	20
Ameloblastoma	1	0			1	5	7
Total	48	34	30	49	86	14	261
Other sub-types	3	0	2	0	6	5	16
% of referrals per referral route							
	GP	A&E	X-ray and imaging department	Orthopaedic and fracture clinic	Other hospital consultant	Other healthcare professional	
Chondrosarcoma	17	6	0	12	15	0	
Osteosarcoma	31	50	47	45	26	36	
Ewing sarcoma	19	32	40	27	36	14	
Chordoma	19	6	7	4	9	0	
Adamantinoma	0	0	3	0	0	0	
Spindle Cell sarcoma of the Bone	4	0	3	0	3	0	
Angiosarcoma of the Bone	0	0	0	0	2	0	
Giant Cell Tumour of Bone	8	6	0	12	7	14	
Ameloblastoma	2	0	0	0	1	36	
		100		100	100	100	
Other sub-types	6	0	7	0	7	36	

Primary bone cancer/tumour type - referral breakdown UK only							
% of referrals per primary bone cancer type							
	GP	A&E	X-ray and imaging department	Orthopaedic and fracture clinic	Other hospital consultant	Other healthcare professional	Unknown/none
Chondrosarcoma	28	7	0	21	45	0	
Osteosarcoma	16	18	15	23	23	5	
Ewing sarcoma	12	14	15	17	40	3	
Chordoma	39	9	9	9	35	0	
Adamantinoma	0	0	100	0	0	0	
Spindle Cell sarcoma of the Bone	33	0	17	0	50	0	
Angiosarcoma of the Bone	0	0	0	0	100	0	
Giant Cell Tumour of Bone	20	10	0	30	30	10	
Ameloblastoma	14	0	0	0	14	71	
						0	
Other sub-types	19	0	13	0	38	31	

Referral by anatomical site

Number of referrals per route						
	GP	A&E	X-ray and imaging department	Orthopaedic and fracture clinic	Other hospital consultant	Other healthcare professional
Upper limbs (C40.0-C40.1)	4	3	4	10	5	2
Lower limbs (C40.2-C40.3)	24	23	19	31	42	3
Head (C41.0-C41.1)	3	1	0		11	7
Vertebral column (C41.2)	4	0	1	1	3	
Ribs, sternum and clavicle (C41.3)	3	2	3	1	7	1
Pelvic bones (C41.4)	12	5	3	7	17	1
Bone, overlapping and unspecified (C40.8-C40.9, C41.8-C41.9)	0	0	0	0	0	0
Total	**50**	**34**	**30**	**50**	**85**	**14**

% referrals per route						
	GP	A&E	X-ray and imaging department	Orthopaedic and fracture clinic	Other hospital consultant	Other healthcare professional
Upper limbs (C40.0-C40.1)	8	8.8	13.3	20	5.9	14.3
Lower limbs (C40.2-C40.3)	48	67.6	63.3	62	49.4	21.4
Head (C41.0-C41.1)	6	2.9	0.0	0	12.9	50.0
Vertebral column (C41.2)	8	0.0	3.3	2	3.5	0.0
Ribs, sternum and clavicle (C41.3)	6	5.9	10.0	2	8.2	7.1
Pelvic bones (C41.4)	24	14.7	10	14	20.0	7.1
Bone, overlapping and unspecified (C40.8-C40.9, C41.8-C41.9)	0	0.0	0	0	0.0	0.0
% of referrals per ICD-10 anatomical code						
Upper limbs (C40.0-C40.1)	**14%**	**11%**	**14%**	**36%**	**18%**	**7%**
Lower limbs (C40.2-C40.3)	**17%**	**16%**	**13%**	**22%**	**30%**	**2%**
Head (C41.0-C41.1)	**14%**	**5%**	**0%**	**0%**	**50%**	**32%**
Vertebral column (C41.2)	**44%**	**0%**	**11%**	**11%**	**33%**	**0%**
Ribs sternum and clavicle (C41.3)	**18%**	**12%**	**18%**	**6%**	**41%**	**6%**
Pelvic bones (C41.4)	**27%**	**11%**	**7%**	**16%**	**38%**	**2%**
Bone, overlapping and unspecified (C40.8-C40.9, C41.8-C41.9)	**0%**	**0%**	**0%**	**0%**	**0%**	**0%**

Stage at diagnosis by referral route

Stage at diagnosis by referral method (number of UK patients)			
	Local	Metastatic	Total
GP	38	9	47
A&E	20	14	34
X-ray and imaging department	25	5	30
Orthopaedic and fracture clinic	34	13	47
Other hospital consultant	64	19	83
Other HCP	10	3	13

Stage at diagnosis by referral method %		
	Local	Metastatic
GP	81%	19%
A&E	59%	41%
X-ray and imaging department	83%	17%
Orthopaedic and fracture clinic	72%	28%
Other hospital consultant	77%	23%
Other HCP	77%	23%

Number of misdiagnoses experienced by patients

Number of alternative diagnoses received by patients							
	0	1	2	3	4	5	6
UK patients	74	159	57	15	5	0	2
% UK patients	24%	51%	18%	5%	2%	0%	1%
Outside the UK patients	132	198	68	20	4	3	0
% outside the UK patients	31%	46%	16%	5%	1%	1%	0%

	Number of misdiagnoses by age - UK						
	0 misdiagnosis	1 misdiagnosis	2 misdiagnoses	3 misdiagnoses	4 misdiagnoses	5 misdiagnoses	6 misdiagnoses
Children	20 (21%)	37 (39%)	22 (23%)	10 (11%)	3 (3%)	0 (0%)	2 (2%)
TYAs	20 (22%)	44 (49%)	23 (26%)	2 (2%)	1 (1%)	0 (0%)	0 (0%)
Adults	34 (27%)	75 (59%)	14 (11%)	3 (2%)	1 (1%)	0 (0%)	0 (0%)
	Number of misdiagnoses by age - outside the UK						
	0 misdiagnosis	1 misdiagnosis	2 misdiagnoses	3 misdiagnoses	4 misdiagnoses	5 misdiagnoses	6 misdiagnoses
Children	34 (29%)	54 (47%)	22 (19%)	5 (4%)	1 (1%)	0 (0%)	0 (0%)
TYAs	35 (26%)	56 (42%)	30 (22%)	7 (5%)	3 (2%)	3 (2%)	0 (0%)
Adults	64 (36%)	98 (51%)	15 (9%)	8 (5%)	0 (0%)	0 (0%)	0 (0%)
	Number of misdiagnoses by age - All patients						
	0 misdiagnosis	1 misdiagnosis	2 misdiagnoses	3 misdiagnoses	4 misdiagnoses	5 misdiagnoses	6 misdiagnoses
Children	26%	43%	21%	7%	2%	0%	1%
TYAs	25%	45%	24%	4%	2%	1%	0%
Adults	32%	54%	10%	4%	0%	0%	0%

Common misdiagnoses

UK	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising	Other
Children responses	6	22	1	40	2	1	4	0	5	1	2	21	4	26
% children responses	6%	23%	1%	43%	2%	1%	4%	0%	5%	1%	2%	22%	4%	28%
TYAs responses	3	30	2	15	1	1	0	2	0	2	2	15	2	25
% TYAs responses	3%	33%	2%	17%	1%	1%	0%	2%	0%	2%	2%	17%	2%	28%
Adult responses	6	12	21	0	1	5	0	3	2	5	3	11	2	45
% adult responses	5%	9%	17%	0%	1%	4%	0%	2%	2%	4%	2%	9%	2%	35%

Outside the UK	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / Migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising	Other
Children responses	3	32	0	27	0	0	8	0	0	1	3	15	0	28
% children responses	3%	28%	0%	23%	0%	0%	7%	0%	0%	1%	3%	13%	0%	24%
TYAs responses	8	43	8	17	2	3	5	0	1	5	6	28	3	35
% TYA responses	6%	32%	6%	13%	1%	2%	4%	0%	1%	4%	4%	21%	2%	26%
Adults responses	11	21	13	0	1	3	2	4	1	1	10	16	5	55
% adult responses	6%	12%	7%	0%	1%	2%	1%	2%	1%	1%	6%	9%	3%	31%

Number of misdiagnoses and diagnostic interval in the UK

Diagnostic internal	**Number of misdiagnoses**						
(Months)	**0**	**1**	**2**	**3**	**4**	**5**	**6**
Less than 1 month	16	27	7	1	1		
1	4	10	6	3			
2	3	20	8	2			1
3	3	21	10	2			
4		7	3	2			1
5	6	5	5		1		
6	1	17	8	2			
7		8					
8	2	7		1			
9		2					
10	1	4		1			
11		2					
12	2	6	1				
13-17	1	5	2		2		
18-23	1	9	2				
24+	2	8	5	1	1		
	Number of misdiagnoses						
Diagnostic interval	**0**	**1**	**2**	**3**	**4**	**5**	**6**
≤1 month	20	37	13	4	1	0	0
>1 month	22	121	44	11	4	0	2

Anatomical sites of primary bone cancer/tumour types

	Adamantinoma	Ameloblastoma	Angiosarcoma of the Bone	Chondrosarcoma	Chordoma	Ewing sarcoma	Giant Cell Tumour of the Bone	Osteosarcoma	Spindle Cell Sarcoma of the Bone	Other	Total / location
Ribs			1	18		29		7			55
Upper limbs				12		19	9	23	2	3	68
Lower limbs	6			31		64	36	181	4		322
Jaw		26				5	1	6			38
Skull				9	8	5	1	2			25
Spine				10	5	9	3	4			31
Pelvic bones				19	15	42	11	9	3		99
Unspecified			2			5				94	101
Total	**6**	**26**	**3**	**99**	**28**	**178**	**61**	**232**	**9**	**97**	**739**

	Total / location	% Adamantinoma	% Ameloblastoma	% Angiosarcoma of the Bone	% Chondrosarcoma	% Chordoma	% Ewing sarcoma	% Giant Cell Tumour of the Bone	% Osteosarcoma	% Cell Sarcoma of the Bone	% Other
Ribs	55	0%	0%	33%	18%	0%	16%	0%	3%	0%	0%
Upper limbs	68	0%	0%	0%	12%	0%	11%	15%	10%	22%	3%
Lower limbs	322	100%	0%	0%	31%	0%	36%	59%	78%	44%	0%
Jaw	38	0%	100%	0%	0%	0%	3%	2%	3%	0%	0%
Skull	25	0%	0%	0%	9%	29%	3%	2%	1%	0%	0%
Spine	31	0%	0%	0%	10%	18%	5%	5%	2%	0%	0%
Pelvic bones	99	0%	0%	0%	19%	54%	24%	18%	4%	33%	0%
Unspecified	101	0%	0%	67%	0%	0%	3%	0%	0%	0%	97%
Total	**739**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

Tumours in the lower limbs

Primary bone cancer type	Total number of each primary bone cancer type	With tumours in the lower limbs	% Patients of each primary bone cancer type in the lower limbs
Adamantinoma	6	6	100%
Ameloblastoma	26		0%
Angiosarcoma of the Bone	3		0%
Chondrosarcoma	99	31	31%
Chordoma	28		0%
Ewing sarcoma	178	64	36%
Giant Cell Tumour of the Bone	61	36	59%
Osteosarcoma	232	181	78%
Spindle Cell Sarcoma of the Bone	9	4	44%
Blank	97	3	3%
Total	739	325	44%

Complete list of symptoms and misdiagnosis for lower limb tumours

Pain symptoms									
	n (n = number of respondents)	**Bone pain - constant**	**Bone pain - intermittent**	**Pain worse at night**	**Pain intensifying with time**	**Pain resistant to painkillers**	**No pain**	Was pain at the tumour site? **YES**	Was pain at the tumour site? **NO**
Children	116	32	73	60	57	32	3	89	25
TYAs	106	34	59	52	59	40	7	84	16
Adults	102	34	59	48	61	29	5	79	20
Blank	1		1	1	1			1	
Total	325	100	192	161	178	101	15	253	61
	%	**Bone pain - constant**	**Bone pain - intermittent**	**Pain worse at night**	**Pain intensifying with time**	**Pain resistant to painkillers**	**No pain**	Was pain at the tumour site? **YES**	Was pain at the tumour site? **NO**
Children	116	28%	63%	52%	49%	28%	3%	77%	22%
TYAs	106	32%	56%	49%	56%	38%	7%	79%	15%
Adults	102	33%	58%	47%	60%	28%	5%	77%	20%
Blank	1								
all	100%	31%	59%	50%	55%	31%	5%	78%	19%

Lump / swelling symptoms							
	n (n = number of respondents)	**A lump or swelling could be felt**	**A lump or swelling could be seen**	**The lump or swelling was painful to touch**	**The lump or swelling felt hot to touch**	**The area over the lump or swelling was red or angry looking**	**No lump**
Children	116	59	60	39	29	9	34
TYAs	106	60	65	30	28	9	26
Adults	102	45	47	26	23	12	36
Blank	1						1
Total	325	164	172	95	80	30	97
	%	**A lump or swelling could be felt**	**A lump or swelling could be seen**	**The lump or swelling was painful to touch**	**The lump or swelling felt hot to touch**	**The area over the lump or swelling was red or angry looking**	**No lump**
Children	116	51%	52%	34%	25%	8%	29%
TYAs	106	57%	61%	28%	26%	8%	25%
Adults	102	44%	46%	25%	23%	12%	35%
Blank	1						
All	100%	50%	53%	29%	25%	9%	30%

Movement symptoms								
	n (n = number of respondents)	**Stiffness / restriction limiting normal activities**	**Limp**	**Unable to walk**	**Bedbound**	**Muscle wasting**	**Issues with balance / more falls**	**No issues with mobility**
Children	116	63	76	17	1	10	11	14
TYAs	106	64	67	23	2	15	13	13
Adults	102	62	68	79	2	13	17	13
Blank	1							1
Total	325	189	211	119	5	38	41	41
	%	**Stiffness / restriction limiting normal activities**	**Limp**	**Unable to walk**	**Bedbound**	**Muscle wasting**	**Issues with balance / more falls**	**No issues with mobility**
Children	116	54%	66%	15%	1%	9%	9%	12%
TYAs	106	60%	63%	22%	2%	14%	12%	12%
Adults	102	61%	67%	77%	2%	13%	17%	13%
Blank	1							
All	100%	58%	65%	37%	2%	12%	13%	13%

General symptoms									
	n (n = number of respondents)	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	116	24	8	5	19	11	36	14	0
TYAs	106	28	16	11	14	9	39	15	0
Adults	102	17	13	10	20	5	40	11	1
Blank	1								
Total	325	69	37	26	53	25	115	40	1
	%	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	116	21%	7%	4%	16%	9%	31%	12%	0%
TYAs	106	26%	15%	10%	13%	8%	37%	14%	0%
Adults	102	17%	13%	10%	20%	5%	39%	11%	1%
Blank	1								
all	100%	21%	11%	8%	16%	8%	35%	12%	0%

Common Misdiagnoses by age													
	n (n = number of respondents)	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Children	116	5	39	1	51	0	0	11	0	3	1	2	26	3
TYAs	106	4	48	2	24	0	0	2	0	0	3	5	17	3
Adults	102	8	20	8	0	0	0	1	0	2	3	8	1	0
Blank	1													
Total	325	17	107	11	75	0	0	14	0	5	7	15	44	6
	%	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / Migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Children	116	4%	34%	1%	44%	0%	0%	9%	0%	3%	1%	2%	22%	3%
TYAs	106	4%	45%	2%	23%	0%	0%	2%	0%	0%	3%	5%	16%	3%
Adults	102	8%	20%	8%	0%	0%	0%	1%	0%	2%	3%	8%	1%	0%
Blank	1													
all	100%	5%	33%	3%	23%	0%	0%	4%	0%	2%	2%	5%	14%	2%

Pain symptoms								
n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma	2	4	2	4	1	0	6	0
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	9	20	12	20	9	3	21	8
Chordoma								
Ewing sarcoma	15	41	38	28	23	2	49	13
Giant Cell Tumour of the Bone	12	24	17	20	12	0	27	8
Osteosarcoma	59	102	90	103	54	9	147	28
Spindle Cell Sarcoma of the Bone	2	0	1	2	1		3	1
%	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	was pain at the tumour site **YES**	was pain at the tumour site **NO**
Adamantinoma	33%	67%	33%	67%	17%	0%	100%	0%
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	9%	20%	12%	20%	9%	3%	21%	8%
Chordoma								
Ewing sarcoma	8%	23%	21%	16%	13%	1%	28%	7%
Giant Cell Tumour of the Bone	20%	39%	28%	33%	20%	0%	44%	13%
Osteosarcoma	25%	44%	39%	44%	23%	4%	63%	12%
Spindle Cell Sarcoma of the Bone	22%	0%	11%	22%	11%	0%	33%	11%

Lump / swelling symptoms						
n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma	4	4	1	0	0	1
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	12	11	4	4	1	14
Chordoma						
Ewing sarcoma	24	27	14	18	8	25
Giant Cell Tumour of the Bone	14	18	11	13	2	13
Osteosarcoma	104	108	63	47	18	44
Spindle Cell Sarcoma of the Bone	3	3	0	0	0	1
%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma	67%	67%	17%	0%	0%	17%
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	12%	11%	4%	4%	1%	14%
Chordoma						
Ewing sarcoma	13%	15%	8%	10%	4%	14%
Giant Cell Tumour of the Bone	23%	30%	18%	21%	3%	21%
Osteosarcoma	45%	47%	27%	20%	8%	19%
Spindle Cell Sarcoma of the Bone	33%	33%	0%	0%	0%	11%

Movement symptoms							
n (n = number of respondents)	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma	2	2	0	0	0	0	1
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma	18	20	6	1	6	5	4
Chordoma							
Ewing sarcoma	28	37	13	1	5	3	9
Giant Cell Tumour of the Bone	25	23	9	1	4	7	3
Osteosarcoma	110	126	35	1	23	23	24
Spindle Cell Sarcoma of the Bone	2	2	1	0	0	2	0
%	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma	33%	33%	0%	0%	0%	0%	17%
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma	18%	20%	6%	1%	6%	5%	4%
Chordoma							
Ewing sarcoma	16%	21%	7%	1%	3%	2%	5%
Giant Cell Tumour of the Bone	41%	38%	15%	2%	7%	11%	5%
Osteosarcoma	47%	54%	15%	0%	10%	10%	10%
Spindle Cell Sarcoma of the Bone	22%	22%	11%	0%	0%	22%	0%

General symptoms								
n (n = number of respondents)	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma	0	0	0	0	0	2	0	0
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	5	6	5	6	2	9	6	0
Chordoma								
Ewing sarcoma	16	14	3	5	7	23	8	0
Giant Cell Tumour of the Bone	6	5	7	8	3	16	7	1
Osteosarcoma	37	13	11	32	11	65	18	0
Spindle Cell Sarcoma of the Bone	1	1	0	1	0	1	0	0

General symptoms								
%	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma	0%	0%	0%	0%	0%	33%	0%	0%
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	5%	6%	5%	6%	2%	9%	6%	0%
Chordoma								
Ewing sarcoma	9%	8%	2%	3%	4%	13%	4%	0%
Giant Cell Tumour of the Bone	10%	8%	11%	13%	5%	26%	11%	2%
Osteosarcoma	16%	6%	5%	14%	5%	28%	8%	0%
Spindle Cell Sarcoma of the Bone	11%	11%	0%	11%	0%	11%	0%	0%

Common misdiagnoses by primary bone cancer type													
n (n = number of respondents)	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma	0	3	0	0	0	0	0	0	0	0	0	0	0
Ameloblastoma													
Angiosarcoma of the Bone													
Chondrosarcoma	5	5	3	2	0	0	0	0	0	0	2	3	0
Chordoma													
Ewing sarcoma	3	22	2	23	0	0	6		1	1	15	0	0
Giant Cell Tumour of the Bone	2	8	1	3	0	0	1	0	1	1	4	5	3
Osteosarcoma	7	68	5	47	0	0	7	0	3	3	7	34	7
Spindle Cell Sarcoma of the Bone	0	1	0	0	0	0	0	0	0	0	0	0	0
%	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma	0%	50%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Ameloblastoma													
Angiosarcoma of the Bone													
Chondrosarcoma	16%	16%	10%	6%	0%	0%	0%	0%	0%	0%	6%	10%	0%
Chordoma													
Ewing sarcoma	5%	34%	3%	36%	0%	0%	9%	0%	2%	2%	23%	0%	0%
Giant Cell Tumour of the Bone	6%	22%	3%	8%	0%	0%	3%	0%	3%	3%	11%	14%	8%
Osteosarcoma	4%	38%	3%	26%	0%	0%	4%	0%	2%	2%	4%	19%	4%
Spindle Cell Sarcoma of the Bone	0%	25%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%

Complete list of symptoms and misdiagnosis for upper limb tumours

Type of primary bone cancer type	Total number of each primary bone cancer type	With tumours in the upper limbs	% Patents of each primary bone cancer type in the upper limbs
Adamantinoma	6		0%
Ameloblastoma	26		0%
Angiosarcoma of the Bone	3		0%
Chondrosarcoma	99	12	12%
Chordoma	28		0%
Ewing sarcoma	178	19	11%
Giant Cell Tumour of the Bone	61	9	15%
Osteosarcoma	232	22	9%
Spindle Cell Sarcoma of the Bone	9	2	22%
Blank	97		0%
Total	**739**	**64**	**9%**

Pain symptoms									
	n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain Intensifying with time	Pain Resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	23	3	10	7	4	3	2	17	2
TYAs	21	9	10	9	9	10	9	17	3
Adults	20	8	8	11	11	10	1	14	6
Total	64	20	28	27	24	23	12	48	11
	%	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	23	13%	43%	30%	17%	13%	9%	74%	9%
TYAs	21	43%	48%	43%	43%	48%	43%	81%	14%
Adults	20	40%	40%	55%	55%	50%	5%	70%	30%
All	100%	31%	44%	42%	38%	36%	19%	75%	17%

Lump/swelling symptoms							
	n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Children	23	9	8	2	5	0	8
TYAs	21	12	14	6	4	1	5
Adults	20	11	11	5	3	0	8
Total	64	32	33	13	12	1	21
	%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Children	23	39%	35%	9%	22%	0%	35%
TYAs	21	57%	67%	29%	19%	5%	24%
Adults	20	55%	55%	25%	15%	0%	40%
All	100%	50%	52%	20%	19%	2%	33%

Movement symptoms								
	n (n = number of respondents)	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	23	8	0	0	0	0	0	2
TYAs	21	11	1	0	0	2	0	6
Adults	20	11	0	0	0	2	0	7
Total	64	30	1	0	0	4	0	15

	%	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	23	35%	0%	0%	0%	0%	0%	9%
TYAs	21	52%	5%	0%	0%	10%	0%	29%
Adults	20	55%	0%	0%	0%	10%	0%	35%
Total	100%	47%	2%	0%	0%	6%	0%	23%

General symptoms									
	n (n = number of respondents)	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	23	3	2	1	6	2	7	2	0
TYAs	21	5	4	1	5	2	7	1	1
Adults	20	2	3	3	4	0	7	2	0
Total	64	10	9	5	15	4	21	5	1
	%	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	23	13%	9%	4%	26%	9%	30%	9%	0%
TYAs	21	24%	19%	5%	24%	10%	33%	5%	5%
Adults	20	10%	15%	15%	20%	0%	35%	10%	0%
Blank	0								
Total	100%	16%	14%	8%	23%	6%	33%	8%	2%

Common misdiagnoses by age														
	n (n = number of respondents)	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Children	23	0	7	0	4	0	0	1	0	0	1	3	4	0
TYAs	21	2	7	0	1	0	0	0	0	0	0	1	5	0
Adults	20	1	3	0	0	0	0	0	0	0	0	3	2	1
Total	64	3	17	0	5	0	0	1	0	0	1	7	11	1
	%	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Children	23	0%	30%	0%	17%	0%	0%	4%	0%	0%	4%	13%	17%	0%
TYAs	21	10%	33%	0%	5%	0%	0%	0%	0%	0%	0%	5%	24%	0%
Adults	20	5%	15%	0%	0%	0%	0%	0%	0%	0%	0%	15%	10%	5%
All	64	5%	27%	0%	8%	0%	0%	2%	0%	0%	2%	11%	17%	2%

Pain symptoms								
n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain Intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	4	4	5	5	5	2	8	3
Chordoma								
Ewing sarcoma	3	13	8	5	6	2	14	4
Giant Cell Tumour of the Bone	3	4	6	5	3	0	6	3
Osteosarcoma	9	6	7	9	7	1	18	1
Spindle Cell Sarcoma of the Bone	1	1	1	1	1	0	2	0

Pain symptoms								
%	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	33%	33%	42%	42%	42%	17%	67%	25%
Chordoma								
Ewing sarcoma	16%	68%	42%	26%	32%	11%	74%	21%
Giant Cell Tumour of the Bone	33%	44%	67%	56%	33%	0%	67%	33%
Osteosarcoma	41%	27%	32%	41%	32%	5%	82%	5%
Spindle Cell Sarcoma of the Bone	50%	50%	50%	50%	50%	0%	100%	0%

Lump/swelling symptoms						
n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	6	6	2	1	1	6
Chordoma						
Ewing sarcoma	10	10	2	3	0	6
Giant Cell Tumour of the Bone	6	6	4	3	0	2
Osteosarcoma	10	11	5	5	0	5
Spindle Cell Sarcoma of the Bone	0	0	0	0	0	2

Lump/swelling symptoms						
%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	50%	50%	17%	8%	8%	50%
Chordoma						
Ewing sarcoma	53%	53%	11%	16%	0%	32%
Giant Cell Tumour of the Bone	67%	67%	44%	33%	0%	22%
Osteosarcoma	45%	50%	23%	23%	0%	23%
Spindle Cell Sarcoma of the Bone	0%	0%	0%	0%	0%	100%

Movement symptoms							
n (n = number of respondents)	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma	5	0	0	0	2	0	5
Chordoma							
Ewing sarcoma	8	1	0	0	1	0	10
Giant Cell Tumour of the Bone	7	0	0	0	1	0	2
Osteosarcoma	9	0	0	0	0	1	8
Spindle Cell Sarcoma of the Bone	1	0	0	0	0	0	0
%	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma	42%	0%	0%	0%	17%	0%	42%

%	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Chordoma							
Ewing sarcoma	42%	5%	0%	0%	5%	0%	53%
Giant Cell Tumour of the Bone	78%	0%	0%	0%	11%	0%	22%
Osteosarcoma	41%	0%	0%	0%	0%	5%	36%
Spindle Cell Sarcoma of the Bone	50%	0%	0%	0%	0%	0%	0%

General symptoms								
n (n = number of respondents)	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	2	3	1	3	0	4	2	0
Chordoma								
Ewing sarcoma	6	4	2	3	4	9	3	0
Giant Cell Tumour of the Bone	1	2	2	3	0	2	0	0
Osteosarcoma	1	1	0	4	0	5	0	1
Spindle Cell Sarcoma of the Bone	0	0	0	2	0	1	0	0
%	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	17%	25%	8%	25%	0%	33%	17%	0%
Chordoma								
Ewing sarcoma	32%	21%	11%	16%	21%	47%	16%	0%
Giant Cell Tumour of the Bone	11%	22%	22%	33%	0%	22%	0%	0%
Osteosarcoma	5%	5%	0%	18%	0%	23%	0%	5%
Spindle Cell Sarcoma of the Bone	0%	0%	0%	100%	0%	50%	0%	0%

Common misdiagnoses by primary bone cancer type													
n (n = number of respondents)	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma													
Ameloblastoma													
Angiosarcoma of the Bone													
Chondrosarcoma	0	1	0	0	0	0	0	0	0	0	1	2	1
Chordoma													
Ewing sarcoma	0	5	0	3	0	0	1	0	0	0	3	4	0
Giant Cell Tumour of the Bone	2	1	0	0	0	0	0	0	0	0	2	0	0
Osteosarcoma	1	9	0	2	0	0	0	0	0	1	1	5	0
Spindle Cell Sarcoma of the Bone	0	0	0	0	0	0	0	0	0	0	0	0	0
%	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache /abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma													
Ameloblastoma													
Angiosarcoma of the Bone													
Chondrosarcoma	0%	8%	0%	0%	0%	0%	0%	0%	0%	0%	8%	17%	8%
Chordoma													
Ewing sarcoma	0%	26%	0%	16%	0%	0%	5%	0%	0%	0%	16%	21%	0%
Giant Cell Tumour of the Bone	22%	11%	0%	0%	0%	0%	0%	0%	0%	0%	22%	0%	0%
Osteosarcoma	5%	41%	0%	9%	0%	0%	0%	0%	0%	5%	5%	23%	0%
Spindle Cell Sarcoma of the Bone	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%

Complete list of symptoms and misdiagnosis for pelvic bones tumours

Primary bone cancer type	Total number of each primary bone cancer type	with tumours in the pelvic bones	% Patients of each primary bone cancer in the pelvic bones
Adamantinoma	6		0%
Ameloblastoma	26		0%
Angiosarcoma of the Bone	3		0%
Chondrosarcoma	99	19	19%
Chordoma	28	15	54%

Primary bone cancer type	Total number of each primary bone cancer type	with tumours in the pelvic bones	% Patients of each primary bone cancer in the pelvic bones
Ewing sarcoma	178	42	24%
Giant Cell Tumour of the Bone	61	11	18%
Osteosarcoma	232	9	4%
Spindle Cell Sarcoma of the Bone	9	3	33%
Blank	97		0%
Total	**739**	**99**	**13%**

Pain symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Constant	21	2	8	11	Constant	21%	15%	28%	19%
Intermittent	46	7	14	25	Intermittent	46%	54%	48%	44%
Worse at night	50	6	18	26	Worse at night	51%	46%	62%	46%
Intensifying with time	56	9	20	27	Intensifying with time	57%	69%	69%	47%
Resistant to painkillers	33	2	14	17	Resistant to painkillers	33%	15%	48%	30%
No pain	4	0	0	4	No pain	4%	0%	0%	7%
Pain at site of tumour					Pain at site of tumour	0%	0%	0%	0%
Y	54	7	16	31	Y	55%	54%	55%	54%
N	40	6	12	22	N	40%	46%	41%	39%
Unknown / no pain	5		1	4	Unknown / no pain	5%	0%	3%	7%

Lump/swelling symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Lump felt	21	3	5	13	Lump felt	21%	23%	17%	23%
Lump Seen	21	5	5	11	Lump Seen	21%	38%	17%	19%
Painful to touch	8	1	3	4	Painful to touch	8%	8%	10%	7%
Hot to touch	3	1	1	1	Hot to touch	3%	8%	3%	2%
Red / angry	3	0	1	2	Red / angry	3%	0%	3%	4%
No lump	70	7	22	41	No lump	71%	54%	76%	72%

Movement symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Stiffness	55	7	14	34	**Stiffness**	56%	54%	48%	60%
Limp	49	8	15	26	**Limp**	49%	62%	52%	46%
Unable to walk	24	2	10	12	**Unable to walk**	24%	15%	34%	21%
Bed bound	5	0	2	3	**Bed bound**	5%	0%	7%	5%
Muscle wasting	7	1	2	4	**Muscle wasting**	7%	8%	7%	7%
Balance	12	1	6	5	**Balance**	12%	8%	21%	9%
No issues	17	0	5	12	**No issues**	17%	0%	17%	21%

General symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Fatigue	46	4	15	27	**Fatigue**	46%	31%	52%	47%
Weight loss	16	2	7	7	**Weight loss**	16%	15%	24%	12%
Fever	15	4	5	6	**Fever**	15%	31%	17%	11%
Headaches	7	1	1	5	**Headaches**	7%	8%	3%	9%
Bruising	5	0	2	3	**Bruising**	5%	0%	7%	5%
Nausea	8	0	2	6	**Nausea**	8%	0%	7%	11%
Bladder / bowel problems	3	1	0	2	**Bladder / bowel problems**	3%	8%	0%	4%
Paralysis / numbness	4	0	0	4	**Paralysis / numbness**	4%	0%	0%	7%
Fracture	7	0	2	5	**Fracture**	7%	0%	7%	9%
Toothache	1	0	0	1	**Toothache**	1%	0%	0%	2%

Cases in the pelvis	Chondrosarcoma	% Chondrosarcoma	Osteosarcoma	% Osteosarcoma	Ewing sarcoma	% Ewing sarcoma	Spindle Cell Sarcoma of the Bone	% Spindle Cell Sarcoma of the Bone	Giant Cell Tumour of Bone	% Giant Cell Tumour of Bone	Chordoma	% Chordoma	Total	% Total
Constant	2	11%	3	33%	6	14%	1	33%	5	45%	4	14%	21	21%
Intermittent	9	47%	2	22%	24	57%	0	0%	4	36%	7	25%	46	46%
Worse at night	11	58%	3	33%	25	60%	0	0%	4	36%	7	25%	50	51%
Intensifying with time	9	47%	5	56%	27	64%	1	33%	8	73%	6	21%	56	57%
Resistant to painkillers	6	32%	2	22%	16	38%	0	0%	5	45%	4	14%	33	33%
No pain	0	0%	0	0%	1	2%	0	0%	0	0%	3	11%	4	4%
Pain in location of tumour?		0%		0%		0%		0%		0%		0%	0	0%
Y	10	53%	6	67%	22	52%	3	100%	5	45%	8	29%	54	55%
N	9	47%	3	33%	18	43%	0	0%	6	55%	4	14%	40	40%
Unknown	0	0%	0	0%	2	5%		0%		0%	3	11%	5	5%
Lump felt	5	26%	2	22%	9	21%	0	0%	2	18%	3	11%	21	21%
Lump Seen	3	16%	2	22%	11	26%	0	0%	2	18%	3	11%	21	21%
Painful to touch	0	0%	1	11%	5	12%	0	0%	0	0%	2	7%	8	8%
hot to touch	0	0%	1	11%	2	5%	0	0%	0	0%	0	0%	3	3%
red/angry	0	0%	0	0%	2	5%	0	0%	1	9%	0	0%	3	3%
No lump	13	68%	6	67%	29	69%	3	100%	9	82%	10	36%	70	71%
Stiffness	8	42%	6	67%	22	52%	0	0%	9	82%	10	36%	55	56%
Limp	9	47%	6	67%	22	52%	3	100%	8	73%	1	4%	49	49%
Unable to walk	4	21%	1	11%	12	29%	0	0%	5	45%	2	7%	24	24%
Bed bound	0	0%	1	11%	3	7%	0	0%	1	9%	0	0%	5	5%
Muscle wasting	1	5%	1	11%	2	5%	0	0%	3	27%	0	0%	7	7%
Balance	2	11%	1	11%	5	12%	0	0%	3	27%	1	4%	12	12%
No issues	6	32%	1	11%	4	10%	0	0%	0	0%	5	18%	16	16%
Fatigue	13	68%	4	44%	21	50%	0	0%	4	36%	4	14%	46	46%
Weightloss	1	5%	0	0%	10	24%	0	0%	3	27%	2	7%	16	16%
Fever	3	16%	1	11%	10	24%	0	0%	0	0%	1	4%	15	15%
Headaches	4	21%	0	0%	2	5%	0	0%	0	0%	1	4%	7	7%
Bruising	3	16%	0	0%	0	0%	0	0%	2	18%	0	0%	5	5%
Nausea	4	21%	1	11%	2	5%	0	0%	0	0%	1	4%	8	8%
Bladder / bowel problems		0%	0	0%	1	2%	0	0%	1	9%	1	4%	3	3%
Paralysis / numbness	1	5%	0	0%	1	2%	0	0%	2	18%	0	0%	4	4%
Rash	1	5%	0	0%		0%	0	0%	0	0%	0	0%	1	1%
Fracture	1	5%	1	11%	2	5%	0	0%	3	27%	0	0%	7	7%
Toothache	1	5%	0	0%	0	0%	0	0%	0	0%	0	0%	1	1%

Misdiagnoses	Chondrosarcoma	Osteosarcoma	Ewing sarcoma	Chordoma	Spindle Cell Sarcoma of the Bone	Giant Cell Tumour of Bone	Total	Chondrosarcoma	Osteosarcoma	Ewing sarcoma	Chordoma	Spindle Cell Sarcoma of the Bone	Giant Cell Tumour of Bone	Total
Arthritis	4	0	7	3	0	0	14	21%	0%	17%	20%	0%	0%	14%
Sporting injury	3	3	12	1	0	1	20	16%	33%	29%	7%	0%	9%	20%
Sciatica / nerve damage	3	3	10	5	1	7	29	16%	33%	24%	33%	33%	64%	29%
Growing pains	0	1	9	0	0	0	10	0%	11%	21%	0%	0%	0%	10%
Pulled muscle	0	1	12	1	0	0	14	0%	11%	29%	7%	0%	0%	14%

Complete list of symptoms and misdiagnosis for tumours in the ribs.

Primary bone cancer type	Total number of each primary bone cancer type	With tumours in the ribs	% Patients of each primary bone cancer type in the ribs
Adamantinoma	6		0%
Ameloblastoma	26		0%
Angiosarcoma of the Bone	3	1	33%
Chondrosarcoma	99	18	18%
Chordoma	28		0%
Ewing sarcoma	178	29	16%
Giant Cell Tumour of the Bone	61		0%
Osteosarcoma	232	7	3%
Spindle Cell Sarcoma of the Bone	9		0%
Blank	97		0%
Total	739	55	7%

Pain symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Constant	16	3	7	6	**Constant**	29%	21%	37%	27%
Intermittent	26	8	10	8	**Intermittent**	47%	57%	53%	36%
Worse at night	29	8	12	9	**Worse at night**	53%	57%	63%	41%
Intensifying with time	30	7	14	9	**Intensifying with time**	55%	50%	74%	41%
Resistant to painkillers	16	4	7	5	**Resistant to painkillers**	29%	29%	37%	23%
No pain	6	1	1	4	**No pain**	11%	7%	5%	18%

Lump / swelling symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Lump felt	27	4	7	14	**Lump felt**	49%	50%	37%	64%
Lump Seen	22	4	7	11	**Lump Seen**	40%	50%	37%	50%
Painful to touch	12	3	5	3	**Painful to touch**	22%	36%	26%	14%
Hot to touch	5	1	1	3	**Hot to touch**	9%	7%	5%	14%
Red / angry	1	0	1	0	**Red / angry**	2%	7%	5%	0%
No lump	22	7	8	7	**No lump**	40%	57%	42%	32%

Movement symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Stiffness	17	2	8	7	**Stiffness**	31%	14%	42%	32%
Limp	1	0	1	0	**Limp**	2%	0%	5%	0%
Unable to walk	1	0	1	0	**Unable to walk**	2%	0%	5%	0%
Bed bound	2	0	2	0	**Bed bound**	4%	0%	11%	0%
Muscle wasting	5	2	1	2	**Muscle wasting**	9%	14%	5%	9%
Balance	1	0	1		**Balance**	2%	0%	5%	0%
No issues	36	11	10	15	**No issues**	65%	79%	53%	68%

General symptoms									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Fatigue	20	7	5	8	**Fatigue**	36%	50%	26%	36%
Weight loss	11	7	3	1	**Weight loss**	20%	50%	16%	5%
Fever	9	3	4	2	**Fever**	16%	21%	21%	9%
Headaches	5	0	2	3	**Headaches**	9%	0%	11%	14%
Bruising	2	1	1	0	**Bruising**	4%	7%	5%	0%
Nausea	1	1		0	**Nausea**	2%	7%	0%	0%
Bladder / bowel	0				**Bladder / bowel**	0%	0%	0%	0%
Paralysis / numbness	0				**Paralysis / numbness**	0%	0%	0%	0%
Breathing	5	1	3	1	**Breathing**	9%	7%	16%	5%
Rash	3		1	2	**Rash**	5%	0%	5%	9%
Fracture	6	2	3	1	**Fracture**	11%	14%	16%	5%

Common misdiagnoses by age									
	n (n = number of respondents)					%			
	Total	Children	TYAs	Adults		Total	Children	TYAs	Adults
Pulled muscle	8	0	7	1	**Pulled muscle**	15%	0%	37%	5%
Sporting injury	11	3	6	2	**Sporting injury**	20%	21%	32%	9%
Growing pains	6	4	2	0	**Growing pains**	11%	29%	11%	0%
Chest infection / asthma	3	2	1	0	**Chest infection / asthma**	5%	14%	5%	0%
Other	33	28	26	25	**Other**	60%	200%	137%	114%
Bone Infection	1	0	0	1	**Bone Infection**	2%	0%	0%	5%
Trapped nerve	2	0	2	0	**Trapped nerve**	4%	0%	11%	0%
Tendonitis	2	0	1	1	**Tendonitis**	4%	0%	5%	5%
Arthritis	1	1	0	0	**Arthritis**	2%	7%	0%	0%
Eye problems	2	2	0	0	**Eye problems**	4%	14%	0%	0%
Irritable hip	1	1	0	0	**Irritable hip**	2%	7%	0%	0%
Bruising	1	1	0	0	**Bruising**	2%	7%	0%	0%

	Chondrosarcoma	Osteosarcoma	Ewing sarcoma	Angiosarcoma of the Bone	Total	Chondrosarcoma	Osteosarcoma	Ewing sarcoma	Angiosarcoma of the Bone	Total
Constant	3	3	9	1	16	17%	43%	31%	100%	29%
Intermittent	7	3	16		26	39%	43%	55%	0%	47%
Pain worse at night	7	5	17		29	39%	71%	59%	0%	53%
Pain intensifying with time	8	3	19		30	44%	43%	66%	0%	55%
Pain resistant to painkillers	2	3	11		16	11%	43%	38%	0%	29%
No pain	4	0	2		6	22%	0%	7%	0%	11%
Pain in location of tumour?						0%	0%	0%	0%	0%
Y	9	7	24		40	50%	100%	83%	0%	73%
N	6	0	3	1	10	33%	0%	10%	100%	18%
Unknown	3	0	2		5	17%	0%	7%	0%	9%
Lump felt	10	7	10		27	56%	100%	34%	0%	49%
Lump Seen	10	3	9		22	56%	43%	31%	0%	40%
Painful to touch	3	2	7		12	17%	29%	24%	0%	22%
Hot to touch	0	1	4		5	0%	14%	14%	0%	9%
Red / angry	0	0	1		1	0%	0%	3%	0%	2%
No lump	6	0	15	1	22	33%	0%	52%	100%	40%
Stiffness	4	2	10	1	17	22%	29%	34%	100%	31%
Limp	1	0	0		1	6%	0%	0%	0%	2%
Unable to walk	0	0	1		1	0%	0%	3%	0%	2%
Bed bound	0	0	2		2	0%	0%	7%	0%	4%
Muscle wasting	2	0	2	1	5	11%	0%	7%	100%	9%
Balance	0	0	1		1	0%	0%	3%	0%	2%
No issues	14	5	17		36	78%	71%	59%	0%	65%
Fatigue	4	3	13		20	22%	43%	45%	0%	36%
Weight loss	1	0	10		11	6%	0%	34%	0%	20%
Fever	1	1	7		9	6%	14%	24%	0%	16%
Headaches	2	2	1		5	11%	29%	3%	0%	9%
Bruising	0	0	1	1	2	0%	0%	3%	100%	4%
Nausea	0	0	1		1	0%	0%	3%	0%	2%
Bladder / bowel		0			0	0%	0%	0%	0%	0%
Paralysis / numbness		0			0	0%	0%	0%	0%	0%
Breathing	2	0	3		5	11%	0%	10%	0%	9%
Rash	1	0	2		3	6%	0%	7%	0%	5%
Fracture	1	1	4		6	6%	14%	14%	0%	11%

Common misdiagnoses by primary bone cancer type								
	Chondrosarcoma	Osteosarcoma	Ewing sarcoma	Chordoma	Total	% Chondrosarcoma	% Osteosarcoma	% Ewing sarcoma
Sporting injury	3	0	4	0	7	17%	0%	14%
Pulled muscle	3	3	7	0	13	17%	43%	24%
Growing pains						0%	0%	0%

Complete list of symptoms and misdiagnosis for tumours in the spine.

Primary bone cancer type	Total number of each primary bone cancer type	With tumours in the Spine	% Patients of each primary bone cancer type in the Spine
Adamantinoma	6		0%
Ameloblastoma	26		0%
Angiosarcoma of the Bone	3		0%
Chondrosarcoma	99	10	10%
Chordoma	28	5	18%
Ewing sarcoma	178	9	5%
Giant Cell Tumour of the Bone	61	3	5%
Osteosarcoma	232	4	2%
Spindle Cell Sarcoma of the Bone	9		0%
Blank	97		0%
Total	739	31	4%

Pain symptoms									
	n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	6		4	4	4	3		3	3
TYAs	7	4	2	7	6	7		4	3
Adults	18	3	6	8	6	3	3	11	6
Total	31	7	12	19	16	13	3	18	12

Pain symptoms									
	%	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	6	0%	67%	67%	67%	50%	0%	50%	50%
TYAs	7	57%	29%	100%	86%	100%	0%	57%	43%
Adults	18	17%	33%	16%	33%	17%	17%	61%	33%
Total	31	23%	39%	61%	52%	42%	10%	58%	39%

Lump / swelling symptoms						
n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Children	2	1	2	1		4
TYAs	2	2				4
Adults	3	2		1		13
Total	7	5	2	2	0	21
%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Children	33%	17%	33%	17%	0%	67%
TYAs	29%	29%	0%	0%	0%	57%
Adults	17%	11%	0%	6%	0%	72%
Total	23%	16%	6%	6%	0%	68%

Movement symptoms								
n (n = number of respondents)		Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	6	3	1	1		1	3	
TYAs	7	4		5	2	3	3	1
Adults	18	11	4	2	1	1	4	3
Blank	0							
Total	31	18	5	8	3	5	10	4
%		Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	6	50%	17%	17%	0%	17%	50%	0%
TYAs	7	57%	0%	71%	29%	43%	43%	14%
Adults	18	61%	22%	11%	6%	6%	22%	17%
Blank	0							
Total	31	58%	16%	26%	10%	16%	32%	13%

General symptoms												
n (n = number of respondents)		Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache	Scoliosis	Paralysed	Loss of strength in limb	Numbness
Children	6	1					3	1			1	1	
TYAs	7	3	1	1			3	1		1			2
Adults	18	3	5	2	1	2	11	1		1			
Blank	0												
Total	31	7	6	3	1	2	17	3	0	2	1	1	2

General symptoms												
%		Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache	Scoliosis	Paralysed	Loss of strength in limb	Numbness
Children	6	17%	0%	0%	0%	0%	50%	17%	0%	0%	17%	17%	0%
TYAs	7	43%	14%	14%	0%	0%	43%	14%	0%	14%	0%	0%	29%
Adults	18	17%	28%	11%	6%	11%	61%	6%	0%	6%	0%	0%	0%
Blank	0												
Total	31	23%	19%	10%	3%	6%	55%	10%	0%	6%	3%	3%	6%

Pain symptoms								
n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	2	3	4	3	2	1	4	6
Chordoma	1	2	3	2	1	1	3	2
Ewing sarcoma	2	5	7	7	5		6	3
Giant Cell tumour of the None		1	1	1	2		3	
Osteosarcoma	2	1	3	3	2	1	1	2
Spindle Cell Sarcoma of the Bone								

%	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	20%	30%	40%	30%	20%	10%	40%	60%
Chordoma	20%	40%	60%	40%	20%	20%	60%	40%
Ewing sarcoma	22%	56%	78%	78%	56%	0%	67%	33%
Giant Cell Tumour of the Bone	0%	33%	33%	33%	67%	0%	100%	0%
Osteosarcoma	50%	25%	75%	75%	50%	25%	25%	50%
Spindle Cell Sarcoma of the Bone								

Lump / swelling symptoms						
n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	4	3		1		5
Chordoma						4
Ewing sarcoma	2	2	2	1		6
Giant Cell Tumour of the Bone						3
Osteosarcoma						3
Spindle Cell Sarcoma of the Bone						
%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	40%	30%	0%	10%	0%	50%
Chordoma	0%	0%	0%	0%	0%	80%
Ewing sarcoma	22%	22%	22%	11%	0%	67%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	100%
Osteosarcoma	0%	0%	0%	0%	0%	75%
Spindle Cell Sarcoma of the Bone						

Movement symptoms							
n (n = number of respondents)	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma	4	2	1	1	1	2	3
Chordoma	4	2				1	
Ewing sarcoma	6	1	4	1	3	3	
Giant Cell Tumour of the Bone	1		1			1	1
Osteosarcoma	3		2	1		3	
Spindle Cell Sarcoma of the Bone							
%	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma	40%	20%	10%	10%	10%	20%	30%
Chordoma	80%	40%	0%	0%	0%	20%	0%
Ewing sarcoma	67%	11%	44%	11%	33%	33%	0%
Giant Cell Tumour of the Bone	33%	0%	33%	0%	0%	33%	33%
Osteosarcoma	75%	0%	50%	25%	0%	75%	0%
Spindle Cell Sarcoma of the Bone							

General symptoms								
n (n = number of respondents)	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	1	1	1		1	5		
Chordoma	1	2		1		4		
Ewing sarcoma	3	2			1	4		
Giant Cell Tumour of the Bone						1	2	
Osteosarcoma	1	1	1			3	1	
Spindle Cell Sarcoma of the Bone								

%	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	10%	10%	10%	0%	10%	50%	0%	0%
Chordoma	20%	40%	0%	20%	0%	80%	0%	0%
Ewing sarcoma	33%	22%	0%	0%	11%	44%	0%	0%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	33%	67%	0%
Osteosarcoma	25%	25%	25%	0%	0%	75%	25%	0%
Spindle Cell Sarcoma of the Bone								

Common misdiagnoses by primary bone cancer type

n (n = number of respondents)	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma													
Ameloblastoma													
Angiosarcoma of the Bone													
Chondrosarcoma	1		1							1		2	
Chordoma		1	3										
Ewing sarcoma		2		3								4	
Giant Cell Tumour of the Bone		1	1							1		2	
Osteosarcoma												1	
Spindle Cell Sarcoma of the Bone													

%	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma													
Ameloblastoma													
Angiosarcoma of the Bone													
Chondrosarcoma	10%	0%	10%	0%	0%	0%	0%	0%	0%	10%	0%	20%	0%
Chordoma	0%	20%	60%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Ewing sarcoma	0%	22%	0%	33%	0%	0%	0%	0%	0%	0%	0%	44%	0%
Giant Cell Tumour of the Bone	0%	33%	33%	0%	0%	0%	0%	0%	0%	33%	0%	67%	0%

%	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendinitis	Pulled muscle	Bruising
Osteosarcoma	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	25%	0%
Spindle Cell Sarcoma of the Bone													

Complete list of symptoms and misdiagnosis for tumours in the head.

Primary bone cancer type	Total number of each primary bone cancer type	With tumours in the jaw	% of each primary bone cancer type in the jaw	With tumours in the skull	% of each primary bone cancer type in the skull
Adamantinoma	6		0%		0%
Ameloblastoma	26	26	100%		0%
Angiosarcoma of the Bone	3		0%		0%
Chondrosarcoma	99		0%	9	9%
Chordoma	28		0%	8	29%
Ewing sarcoma	178	5	3%	5	3%
Giant Cell Tumour of the Bone	61	1	2%	1	2%
Osteosarcoma	232	6	3%	2	1%
Spindle Cell Sarcoma of the Bone	9		0%		0%
Blank	97		0%		0%
Total	739	38	5%	25	3%

Symptoms in the skull

Pain symptoms									
n (n = number of respondents)		Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	5	1	2	2	1	2	1	4	1
TYAs	7		1				2		
Adults	13	3	2	1	3	1	4	7	4
Total	25	4	5	3	4	3	7	11	5
%		Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain Intensifying with time	Pain Resistant to painkillers	No Pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	5	20%	40%	40%	20%	40%	20%	80%	20%
TYAs	7	0%	14%	0%	0%	0%	29%	0%	0%
Adults	13	23%	15%	8%	23%	8%	31%	54%	31%
Total	25	16%	20%	12%	16%	12%	28%	44%	20%

Lump / swelling symptoms						
n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Children	3	2	1	1		1
TYAs	3	2				2
Adults		1				11
Total	6	5	1	1	0	14

%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Children	60%	40%	20%	20%	0%	20%
TYAs	43%	29%	0%	0%	0%	29%
Adults	0%	8%	0%	0%	0%	85%
Total	24%	20%	4%	4%	0%	56%

Movement symptoms								
n (n = number of respondents)		Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	5	1					1	3
TYAs	7					1	1	4
Adults	13	1					2	9
Total	25	2	0	0	0	1	4	16
%		Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	5	20%	0%	0%	0%	0%	20%	60%
TYAs	7	0%	0%	0%	0%	14%	14%	57%
Adults	13	8%	0%	0%	0%	0%	15%	69%
Total	25	8%	0%	0%	0%	4%	16%	64%

General symptoms									
n (n = number of respondents)		Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	5	1	2				2	1	
TYAs	7	1	1				3	7	
Adults	13	1				3		7	
Total	25	3	3	0	0	3	5	15	0

General symptoms									
%		Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	5	20%	40%	0%	0%	0%	40%	20%	0%
TYAs	7	14%	14%	0%	0%	0%	43%	100%	0%
Adults	13	8%	0%	0%	0%	23%	0%	54%	0%
Total	25	12%	12%	0%	0%	12%	20%	60%	0%

Common misdiagnoses by age														
n (n = number of respondents)		Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising	Sinus / ear infection
Children	5						1						1		1
TYAs	7		1			3			2						
Adults	13					2			4		1		1		2
Total	25	0	1	0	0	5	1	0	6	0	1	0	2	0	3
%		Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / Migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising	Sinus / ear infection
Children	5	0%	0%	0%	0%	0%	20%	0%	0%	0%	0%	0%	20%	0%	20%
TYAs	7	0%	14%	0%	0%	43%	0%	0%	29%	0%	0%	0%	0%	0%	0%
Adults	13	0%	0%	0%	0%	15%	0%	0%	31%	0%	8%	0%	8%	0%	15%
Total	25	0%	4%	0%	0%	20%	4%	0%	24%	0%	4%	0%	8%	0%	12%

Pain symptoms								
n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	2	3	1	2	1	2	6	2
Chordoma	2		2	2	2	4	2	4

n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Ewing sarcoma		2			1	2	3	1
Giant Cell Tumour of the Bone							1	
Osteosarcoma		1		1			1	1
Spindle Cell Sarcoma of the Bone								
Total	4	6	3	5	4	8	13	8
%	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain Intensifying with time	Pain Resistant to painkillers	No Pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma								
Angiosarcoma of the Bone								
Chondrosarcoma	22%	33%	11%	22%	11%	22%	67%	22%
Chordoma	25%	0%	25%	25%	25%	50%	25%	50%
Ewing sarcoma	0%	40%	0%	0%	20%	40%	60%	20%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	0%	100%	0%
Osteosarcoma	0%	50%	0%	50%	0%	0%	50%	50%
Spindle Cell Sarcoma of the Bone								
Total	16%	24%	12%	20%	16%	32%	52%	32%

Lump / swelling symptoms						
n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	2	2				7
Chordoma	1		1			6
Ewing sarcoma	2	3			1	
Giant Cell Tumour of the Bone						1
Osteosarcoma		1				
Spindle Cell Sarcoma						
Total	5	6	1	0	1	14

Lump / swelling symptoms						
%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma						
Angiosarcoma of the Bone						
Chondrosarcoma	22%	22%	0%	0%	0%	78%
Chordoma	13%	0%	13%	0%	0%	75%
Ewing sarcoma	40%	60%	0%	0%	20%	0%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	100%
Osteosarcoma	0%	50%	0%	0%	0%	0%
Spindle Cell Sarcoma of the Bone						
Total	20%	24%	4%	0%	4%	56%

Movement symptoms							
n (n = number of respondents)	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma						1	7
Chordoma	2				1	1	2
Ewing sarcoma						1	4
Giant Cell Tumour of the Bone						1	
Osteosarcoma							2
Spindle Cell Sarcoma of the Bone							
Total	2	0	0	0	1	4	15

Movement symptoms							
%	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma							
Angiosarcoma of the Bone							
Chondrosarcoma	0%	0%	0%	0%	0%	11%	78%
Chordoma	25%	0%	0%	0%	13%	13%	25%
Ewing sarcoma	0%	0%	0%	0%	0%	20%	80%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	100%	0%
Osteosarcoma	0%	0%	0%	0%	0%	0%	100%
Spindle Cell Sarcoma							
Total	8%	0%	0%	0%	4%	16%	60%

General symptoms									
n (n = number of respondents)	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache	Eye problems
Adamantinoma									
Ameloblastoma									
Angiosarcoma of the Bone									
Chondrosarcoma					3	1	8		
Chordoma	1				1		3		2
Ewing sarcoma	1	3				3	5		
Giant Cell Tumour of the Bone	1					1	1		
Osteosarcoma							2		
Spindle Cell Sarcoma of the Bone									
Total	3	3	0	0	4	5	19	0	2

General symptoms									
%	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache	Eye problems
Adamantinoma									
Ameloblastoma									
Angiosarcoma of the Bone									
Chondrosarcoma	0%	0%	0%	0%	33%	11%	89%	0%	
Chordoma	13%	0%	0%	0%	13%	0%	38%	0%	
Ewing sarcoma	20%	60%	0%	0%	0%	60%	100%	0%	
Giant Cell Tumour of the Bone	100%	0%	0%	0%	0%	100%	100%	0%	
Osteosarcoma	0%	0%	0%	0%	0%	0%	100%	0%	
Spindle Cell Sarcoma of the Bone									
Total	12%	12%	0%	0%	16%	20%	76%	0%	8%

Common misdiagnoses by primary bone cancer type														
n (n = number of respondents)	**Arthritis**	**Sporting injury**	**Sciatica / slipped disk**	**Growing pains**	**Eye problems**	**Toothache / abscess**	**Bone infection**	**Headaches / migraines**	**Irritable hip**	**Trapped nerve**	**Tendonitis**	**Pulled muscle**	**Bruising**	**Sinus / ear infection**
Adamantinoma														
Ameloblastoma														
Angiosarcoma of the Bone														
Chondrosarcoma					2			4						2
Chordoma		1			2					1		2		
Ewing sarcoma						1		1						1
Giant Cell tumour of the Bone					1			1						
Osteosarcoma														
Spindle Cell Sarcoma of the Bone														
Total	0	1	0	0	5	1	0	6	0	1	0	2	0	3
%	**Arthritis**	**Sporting injury**	**Sciatica / slipped disk**	**Growing pains**	**Eye problems**	**Toothache / abscess**	**Bone infection**	**Headaches / migraines**	**Irritable hip**	**Trapped nerve**	**Tendonitis**	**Pulled muscle**	**Bruising**	**Sinus / ear infection**
Adamantinoma														
Ameloblastoma														
Angiosarcoma of the Bone														
Chondrosarcoma	0%	0%	0%	0%	11%	0%	0%	21%	0%	0%	0%	0%	0%	11%
Chordoma	0%	13%	0%	0%	25%	0%	0%	0%	0%	13%	0%	25%	0%	0%
Ewing sarcoma	0%	0%	0%	0%	0%	20%	0%	20%	0%	0%	0%	0%	0%	20%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	100%	0%	0%	100%	0%	0%	0%	0%	0%	0%
Osteosarcoma	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Spindle Cell Sarcoma of the Bone														

Symptoms in the Jaw

Pain symptoms									
n (n = number of respondents)		**Bone pain - constant**	**Bone pain - intermittent**	**Pain worse at night**	**Pain Intensifying with time**	**Pain resistant to painkillers**	**No pain**	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	5	1			1		2	1	1
TYAs	9	1	1	1	1		6	3	4
Adults	24	4	5	3	3		12	13	3
Total	38	6	6	4	5	0	20	17	8
%		**Bone pain - constant**	**Bone pain - intermittent**	**Pain worse at night**	**Pain intensifying with time**	**Pain resistant to painkillers**	**No pain**	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Children	5	20%	0%	0%	20%	0%	40%	20%	20%
TYAs	9	11%	11%	11%	11%	0%	67%	33%	44%
Adults	24	17%	21%	13%	13%	0%	50%	54%	13%
Total	38	16%	16%	11%	13%	0%	53%	45%	21%

Lump / swelling symptoms							
n (n = number of respondents)		**A lump or swelling could be felt**	**A lump or swelling could be seen**	**The lump or swelling was painful to touch**	**The lump or swelling felt hot to touch**	**The area over the lump or swelling was red or angry looking**	**No lump**
Children	5	4	4	1		1	1
TYAs	9	7	7	1		2	
Adults	24	16	12	5		3	4
Total	38	27	23	7	0	6	5
%		**A lump or swelling could be felt**	**A lump or swelling could be seen**	**The lump or swelling was painful to touch**	**The lump or swelling felt hot to touch**	**The area over the lump or swelling was red or angry looking**	**No lump**
Children	5	80%	80%	20%	0%	20%	20%
TYAs	9	78%	78%	11%	0%	22%	0%
Adults	24	67%	50%	21%	0%	13%	17%
Total	38	71%	61%	18%	0%	16%	13%

Movement symptoms								
n (n = number of respondents)		Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	5							5
TYAs	9						1	7
Adults	24							21
Total	38	0	0	0	0	0	1	33
%		Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Children	5	0%	0%	0%	0%	0%	0%	100%
TYAs	9	0%	0%	0%	0%	0%	11%	78%
Adults	24	0%	0%	0%	0%	0%	0%	88%
Total	38	0%	0%	0%	0%	0%	3%	87%

General symptoms									
n (n = number of respondents)		Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	5					1			
TYAs	9	2	1				2		5
Adults	24			1		1		4	12
Blank	0								
Total	38	2	1	1	0	2	2	4	17
%		Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Children	5	0%	0%	0%	0%	20%	0%	0%	0%
TYAs	9	22%	11%	0%	0%	0%	22%	0%	56%
Adults	24	0%	0%	4%	0%	4%	0%	17%	50%
Blank	0								
Total	38	5%	3%	3%	0%	5%	5%	11%	45%

Common misdiagnoses by age													
n (n = number of respondents)		Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Children	5													
TYAs	9						3							
Adults	24						8		1					
Total	38	0	0	0	0	0	11	0	1	0	0	0	0	0
%		Arthritis	porting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Children	5	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
TYAs	9	0%	0%	0%	0%	0%	33%	0%	0%	0%	0%	0%	0%	0%
Adults	24	0%	0%	0%	0%	0%	33%	0%	4%	0%	0%	0%	0%	0%
Total	38	0%	0%	0%	0%	0%	29%	0%	3%	0%	0%	0%	0%	0%

Pain symptoms								
n (n = number of respondents)	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma	4	6	3	3		13	14	6
Angiosarcoma of the Bone								
Chondrosarcoma								
Chordoma								
Ewing sarcoma	1			3				
Giant Cell Tumour of the Bone						1		
Osteosarcoma	1			1		3	2	1
Spindle Cell Sarcoma of the Bone								
Total	6	6	3	7	0	17	16	7

Pain symptoms								
%	Bone pain - constant	Bone pain - intermittent	Pain worse at night	Pain intensifying with time	Pain resistant to painkillers	No pain	Was pain at the tumour site **YES**	Was pain at the tumour site **NO**
Adamantinoma								
Ameloblastoma	15%	23%	12%	12%	0%	50%	54%	23%
Angiosarcoma of the Bone								
Chondrosarcoma								
Chordoma								
Ewing sarcoma	20%	0%	0%	60%	0%	0%	0%	0%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	100%	0%	0%
Osteosarcoma	17%	0%	0%	17%	0%	50%	33%	17%
Spindle Cell Sarcoma of the Bone								
Total	16%	16%	8%	18%	0%	45%	42%	18%

Lump / swelling symptoms						
n (n = number of respondents)	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma	17	13	6		4	4
Angiosarcoma of the Bone						
Chondrosarcoma						
Chordoma						
Ewing sarcoma	4	4	1		2	1
Giant Cell Tumour of the Bone	1					
Osteosarcoma	5	6				
Spindle Cell Sarcoma of the Bone						
Total	27	23	7	0	6	5

Lump / swelling symptoms						
%	A lump or swelling could be felt	A lump or swelling could be seen	The lump or swelling was painful to touch	The lump or swelling felt hot to touch	The area over the lump or swelling was red or angry looking	No lump
Adamantinoma						
Ameloblastoma	65%	50%	23%	0%	15%	15%
Angiosarcoma of the Bone						
Chondrosarcoma						
Chordoma						
Ewing sarcoma	80%	80%	20%	0%	40%	20%
Giant Cell Tumour of the Bone	100%	0%	0%	0%	0%	0%
Osteosarcoma	83%	100%	0%	0%	0%	0%
Spindle Cell Sarcoma						
Total	71%	61%	18%	0%	16%	13%

Movement symptoms							
n (n = number of respondents)	Stiffness / restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma						1	22
Angiosarcoma of the Bone							
Chondrosarcoma							
Chordoma							
Ewing sarcoma							5
Giant Cell Tumour of the Bone							1
Osteosarcoma							5
Spindle Cell Sarcoma of the Bone							
Total	0	0	0	0	0	1	33

%	Stiffness/ restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Adamantinoma							
Ameloblastoma	0%	0%	0%	0%	0%	4%	85%
Angiosarcoma of the Bone							

%	Stiffness/ restriction limiting normal activities	Limp	Unable to walk	Bed bound	Muscle wasting	Issues with balance / more falls	No issues with mobility
Chondrosarcoma							
Chordoma							
Ewing sarcoma	0%	0%	0%	0%	0%	0%	100%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	0%	100%
Osteosarcoma	0%	0%	0%	0%	0%	0%	83%
Spindle Cell Sarcoma of the Bone							
Total	0%	0%	0%	0%	0%	3%	87%

General symptoms

n (n = number of respondents)	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma								
Ameloblastoma	1	1	1		1	5	3	16
Angiosarcoma of the Bone								
Chondrosarcoma								
Chordoma								
Ewing sarcoma					1	1	1	
Giant Cell Tumour of the Bone								
Osteosarcoma	1						1	
Spindle Cell Sarcoma of the Bone								
Total	2	1	1	0	2	6	5	16

%	Weight loss	Fever or sweating	Bruising easily	Bone fracture	Nausea	Fatigue	Headaches / migraines	Toothache
Adamantinoma								
Ameloblastoma	4%	4%	4%	0%	4%	19%	12%	62%
Angiosarcoma of the Bone								
Chondrosarcoma								
Chordoma								
Ewing sarcoma	0%	0%	0%	0%	20%	20%	20%	0%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	0%	0%	0%
Osteosarcoma	17%	0%	0%	0%	0%	0%	17%	0%
Spindle Cell Sarcoma of the Bone								
Total	5%	3%	3%	0%	5%	16%	13%	42%

Common misdiagnoses by primary bone cancer type

n (n = number of respondents)	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma													
Ameloblastoma	1					9		1					
Angiosarcoma of the Bone													
Chondrosarcoma													
Chordoma													
Ewing sarcoma													
Giant Cell Tumour of the Bone													
Osteosarcoma						3							
Spindle Cell Sarcoma of the Bone													

%	Arthritis	Sporting injury	Sciatica / slipped disk	Growing pains	Eye problems	Toothache / abscess	Bone infection	Headaches / migraines	Irritable hip	Trapped nerve	Tendonitis	Pulled muscle	Bruising
Adamantinoma													
Ameloblastoma	4%	0%	0%	0%	0%	35%	0%	4%	0%	0%	0%	0%	0%
Angiosarcoma of the Bone													
Chondrosarcoma													
Chordoma													
Ewing sarcoma	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Giant Cell Tumour of the Bone	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Osteosarcoma	0%	0%	0%	0%	0%	50%	0%	0%	0%	0%	0%	0%	0%
Spindle Cell Sarcoma of the Bone													

Surgery LSS versus amputation

UK					
Age	Amputation	Limb salvage surgery (LSS)	Rotationplasty	% amputations UK	% LSS UK
0-4				0%	0%
5-9	2	12	1	1%	6%
10-14	15	25		7%	12%
15-19	17	27		8%	13%
20-24	5	12		2%	6%
25-29	2	10		1%	5%

UK					
Age	**Amputation**	**Limb salvage surgery (LSS)**	**Rotationplasty**	**% amputations UK**	**% LSS UK**
30-34	2	5		1%	2%
35-39	1	5		0%	2%
40-44	3	6		1%	3%
45-49		4		0%	2%
50-54	1	6		0%	3%
55-59	3	4		1%	2%
60-64		2		0%	1%
65-69				0%	0%
70-74				0%	0%
75-79				0%	0%
80+				0%	0%
	51	118	1	25%	58%

Outside the UK					
Age	**Amputation**	**LSS**	**Rotationplasty**	**% amputations of the UK**	**% LSS**
0-4	2	2	1	1%	1%
5-9	5	8	3	2%	3%
10-14	9	34	2	4%	13%
15-19	6	36	1	2%	14%
20-24	2	8		1%	3%
25-29	2	8		1%	3%
30-34	2	12		1%	5%
35-39	3	8	1	1%	3%
40-44	1	8		0%	3%
45-49		7		0%	3%
50-54	2	4		1%	2%
55-59	1	2		0%	1%
60-64		3		0%	1%
65-69	1	2		0%	1%
70-74		1		0%	0%
75-79				0%	0%
80+				0%	0%
	36	143	8	14%	56%

UK	Amputations	LSS	Ratio amputation/LSS
Children	17 (8%)	37 (18%)	0.46
TYA	22 (11%)	39 (19%)	0.56
Adults	12 (6%)	42 (21%)	0.29
all	51 (25%)	118 (58%	0.43

Outside the UK	Amputations	LSS	Ratio amputation/LSS
Children	16 (6%)	44 (17%)	0.36
TYA	8 (3%)	44 (17%)	0.18
Adults	12 (5%)	55 (21%)	0.22
all	36 (14%)	143 (56%)	0.25

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