

Diagnosis: Insights from Sarcoma UK and the Bone Cancer Research Trust

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Why focus on diagnosis?

"I initially went to the GP with a small lump on my left foot, which was dismissed, even when it continued to increase in size."

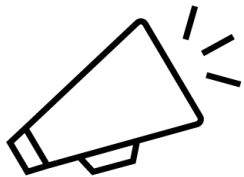
"If only one clinician that saw my Dad along his journey to diagnosis had thought about the possibility of sarcoma, they might have saved his life"

"It took me 6 years to be diagnosed. When I was 15 or 16, I was going to the doctors every week and still no-one knew what was wrong or that it could have been sarcoma"

- As patient facing charities, we regularly hear about **long and distressing waits** for a diagnosis.
- Data on sarcoma **diagnosis is poor**.
- Catching tumours early, at a smaller size means less chance of metastasis and **improved outcomes**.

National Sarcoma Survey 2020

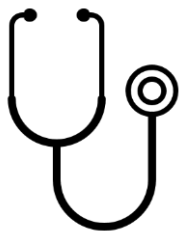
1,117 patients, parents, families and carers



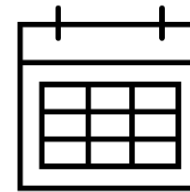
79% of adult patients had not heard of sarcoma before their diagnosis.



14% took **more than 6 months** to make their first visit to a healthcare professional



35% of patients had to see a healthcare professional **more than 3 times** before they were referred for further tests.



30% took more than **6 months** to receive an accurate diagnosis, with **17%** waiting more than **a year**.



At this first appointment, **39%** of adult respondents were either started on **treatment for something else** or were told their **symptoms weren't serious**.

1. National Sarcoma Survey 2020

2. Literature Review

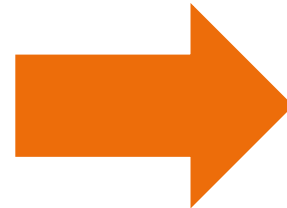
- *Peer-reviewed journal articles and clinical trials.*
- *Literature from cancer advocacy and government health bodies.*

3. Direct patient and carer input

- *Zoom/telephone interviews and focus groups*

4. Clinician input

- Through zoom/telephone interviews and an online survey



Delays cost lives

A call to policy makers to improve early diagnosis of sarcoma

Recommendations

1. Healthcare Professional Education
2. Public Awareness
3. Effective Referrals and Scans

What are the next steps for Sarcoma UK?

- **Building Early Diagnosis into our strategy**
- **Creation of an Expert Steering Group**
Made up of advocates from across the sarcoma community, who will monitor and guide progress of our early diagnosis work.
- **Primary Care Professional Education**
GatewayC education resource in development
- **Working in collaboration...**



Our long-term vision

All people with sarcoma will be diagnosed earlier, have better experiences and live longer lives with less long-term effects.

What this means for people affected by sarcoma



Patients will be
diagnosed earlier
(at stage I or II)



Patients will live longer



Patients will have
better experiences
of their sarcoma

2020 Patient Survey

The 2020 Patient Survey is the most comprehensive analysis of the symptoms and diagnostic experiences for primary bone cancer patients to date.

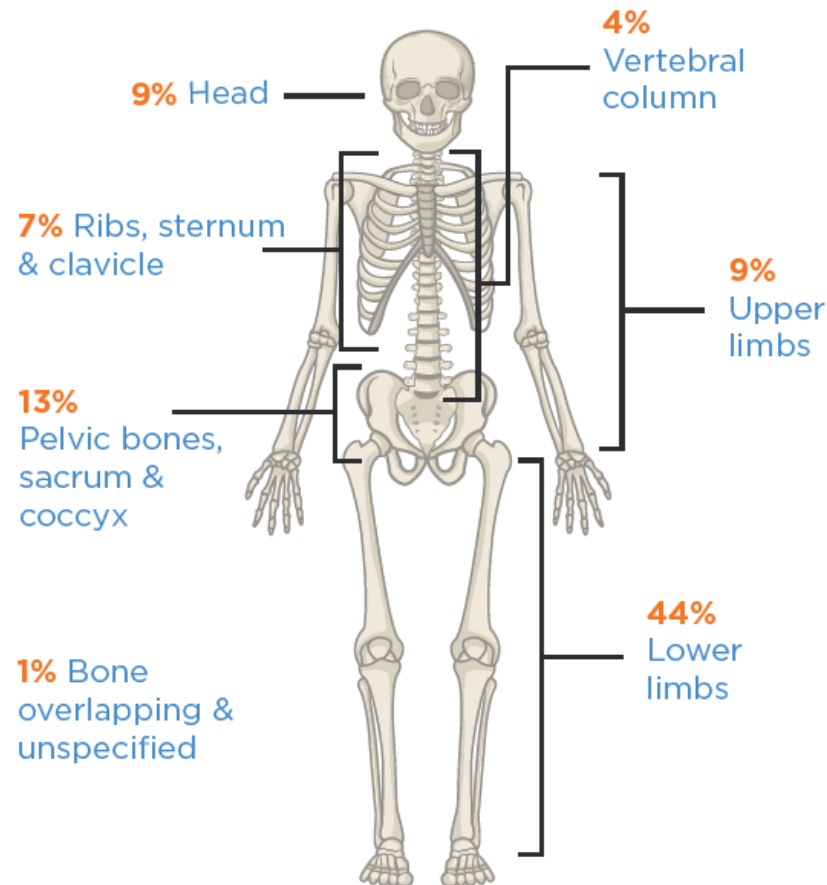


**2020
PATIENT
SURVEY**

- The objectives are **to provide healthcare professionals with the tools they need to recognise the symptoms of primary bone cancer** and to emphasise their **referral pathways**.
- Building on our 2018 Patient Survey and to substantiate the campaign, in July 2020, we carried out a more in-depth survey.



Anatomical location of tumours



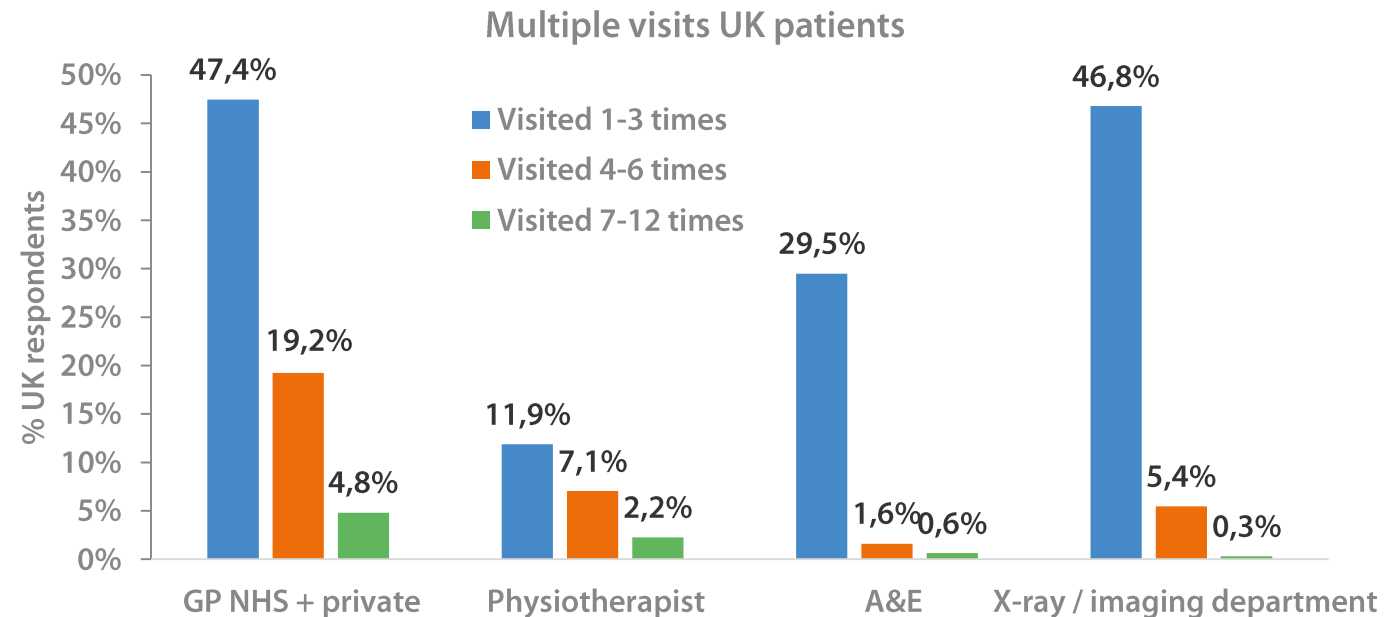
- Of patients experiencing bone pain, 32% suffered **referred pain** - pain at a different anatomical location to the tumour.
- This emphasises the importance of imaging the correct area.
- General symptoms: 32% reported **fatigue**.
- Need to look at the symptoms in combination.

Where did patients present? How long did it take to receive a diagnosis?

76% of patients in the UK first reported their symptoms to a GP and 11 % attended A&E

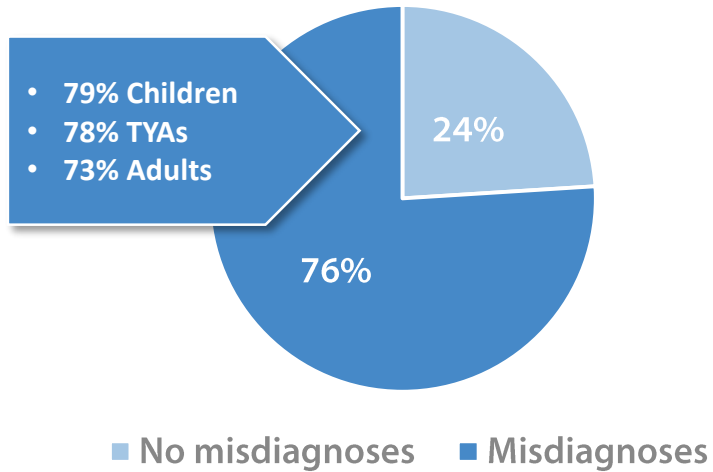
Average number of visits to any healthcare professional

- **8.2 visits** (UK)
- **6.5 visits** (outside the UK) (p =0.0035)



Average number of visits to a GP in the UK was **4.0**

% UK patients



**THE % OF CHILDREN
DIAGNOSED WITH
GROWING PAINS**

IN THE UK (43%)

IS ALMOST TWICE
THAN FOR CHILDREN

**OUTSIDE
THE UK (23%)**

Diagnoses

Many patients received non-diagnoses, misdiagnoses and alternative explanations for their symptoms

- **Growing pains** for children and teenagers.
- **Sporting injury** and **pulled muscles** were the most common misdiagnoses reported for all ages.
- **Arthritis** and **sciatica** were also reported.
- In tumours of the jaw and skull; **migraines**, **tooth abscess** and **ear and sinus infections** were commonly misdiagnosed.

Time to diagnosis

Patient interval

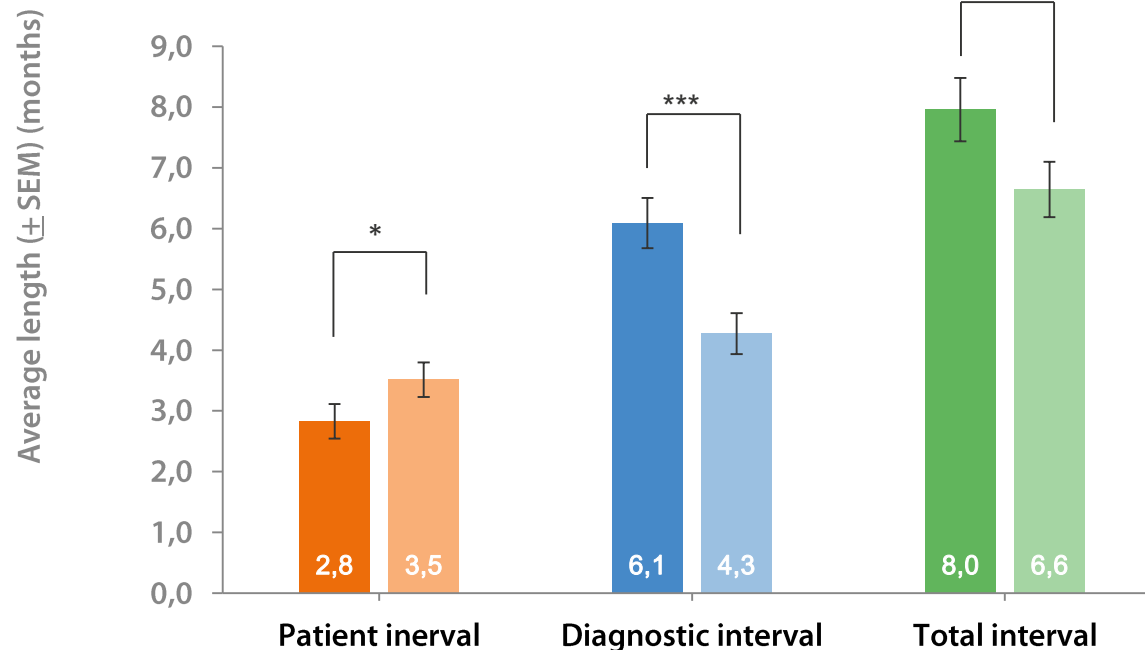


Diagnostic interval



Total interval

Patient Diagnostic and Total intervals UK vs Outside the UK



PATIENTS IN THE UK
VISIT A HEALTHCARE
PROFESSIONAL
**ON AVERAGE
8.2 TIMES**
BEFORE BEING REFERRED,

**26% MORE THAN
OUTSIDE THE UK**

WE WANT HEALTHCARE
PROFESSIONALS TO AIM
TO BE MADE WITHIN

**FOR A DIAGNOSIS
1 MONTH**



IT IS CURRENTLY OVER
6 MONTHS

Maximum waiting times for urgent cancer referrals

The maximum waiting time for suspected cancer is 2 weeks from the day your appointment is booked through the NHS e-Referral Service, or when the hospital or service receives your referral letter.

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graph TD
    Title[Primary Bone Cancer Flashcard] --> Clinical[Clinical Presentations]
    Title --> Investigations[Investigations]
    Clinical --> Risk[Risk Factors]
    Clinical --> NICE[NICE Guidelines Red Flag Symptoms]
    Clinical --> WhatToDo[What to do if you suspect a primary bone cancer:]
    Investigations --> WhatToDo
    Risk --> WhatToDo
    NICE --> WhatToDo
```

Primary Bone Cancer Flashcard

Clinical Presentations

- Bone pain
 - Worse at night**
 - Constant or intermittent
 - Resistant to analgesia
 - May increase in intensity
- Atypical bone or soft tissue swelling / masses**
- Pathological fractures**
- Mobility issues - unexplained limp, joint stiffness, reduced ROM
- Easy bruising
- Inflammation and tenderness over the bone
- Systemic symptoms (most commonly fatigue)

Investigations

- Plain X-ray is the first line investigation (normal X-ray does NOT rule out primary bone cancer)
- If pain is persistent consider MRI if X-ray is clear
 - Bloods: ESR, ALP, LDH, FBC, U&Es, Ca²⁺
 - If >40+ yrs, CT Abdo, Pelvis to rule out a source of metastatic bone cancer
 - Biochemistry diagnostic investigation

Radiological Features

- Bone destruction
- New bone formation
- Soft tissue swelling
- Periosteal elevation

Risk Factors

- Previous radiotherapy
- Previous primary bone cancer
- Paget's disease of bone
- Childhood cancer
- Germ-line abnormalities
- Benign bone lesions

NICE Guidelines Red Flag Symptoms

- Severe pain
- Weight loss
- Neurological symptoms

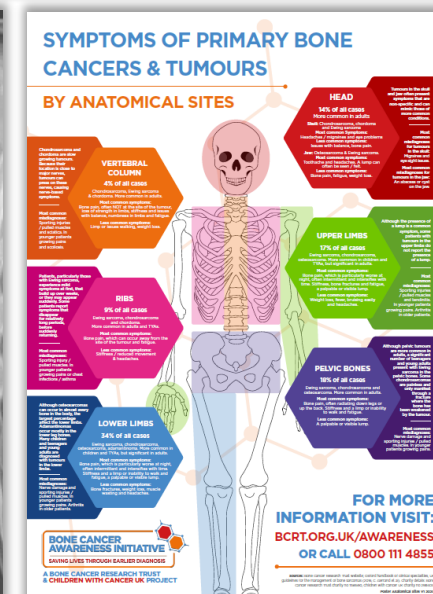
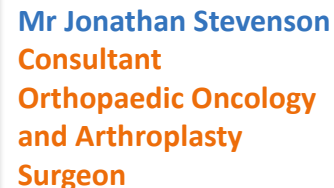
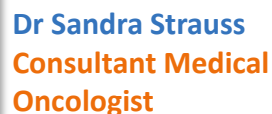
What to do if you suspect a primary bone cancer:

Refer for Plain X-ray via 2 week wait (adult) or within 48 hours (child).

If the results look **indicatory or suspicious for primary bone cancer** Refer directly to a specialist Bone Cancer Centre. For details on these, visit bcrtonline.org/awareness

If the results look **negative or clear** If symptoms persist, refer for further imaging including MRI with 2 week wait (adult) or within 48 hours (child).

- | | |
|--|------------------------|
| 12,811
Pharmacies | 10,771
GP surgeries |
| 586
Physiotherapy practices | 44
Medical Schools |
| 1,542
Hospitals/radiology departments | |



Working in Partnership



- Monthly meetings to **share ideas and progress**.
- Identified **Healthcare Professional Education** as a priority area.
- **Medical students chosen as an early priority**.



- From 2018 Bone Cancer Research Trust began hosting students from the University of Sheffield Medical School to conduct research projects.
- Previous topics included the impact of surgery and emotional wellbeing

In 2020 some of the students focused on diagnosis and Bone Cancer Research Trust invited Sarcoma UK to collaborate

- Designing a survey for medical students
- Exploring how medical students prefer to learn
- What existing sarcoma learning tools/ modules exist and how they could be adapted

Medical Student Survey



Sorrel Bickley @Sorrel_Bickley · Mar 11

Great news! @Sarcoma_UK and @BCRT are joining forces to improve medical student education on sarcoma. Early diagnosis is so important for sarcoma patients, and this work is going to make a difference. #DelaysCostLives.



Bone Cancer Research Trust @BCRT · Mar 9

We're delighted to announce that we have teamed up with @Sarcoma_UK to launch a new collaboration, aiming to increase awareness of sarcoma amongst medical students. 🧑🏻‍🎓 🧑🏻‍🎓

If you are a medical student and want to take part or to find out more, visit ow.ly/g4JH50DUgmE

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Bone Cancer Research Trust & Sarcoma UK launch Sarcoma Awareness Survey for Medical Students

22 February 2021

The Bone Cancer Research Trust and Sarcoma UK are launching a new collaboration, aiming to increase awareness of sarcoma amongst medical students. The first stage of the collaboration builds on awareness work being undertaken by both charities, the launch of a survey to collect data from medical students across the UK to inform next stages of the project.



News
[Archives](#)

News

2021

April

March

February

January

2020

December

November

October

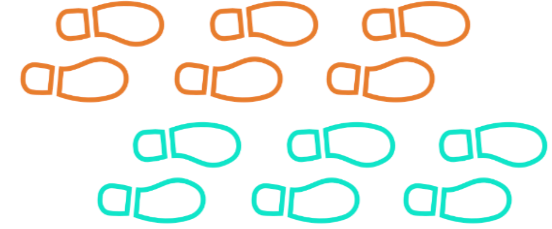
September

August

July

June

The next steps...



- Working on analysis of medical student survey.
- More collaborative work on Sheffield medical student projects.
- Bone Cancer Research Trust developing a new 5 year strategic plan.
- Sarcoma UK Early Diagnosis Expert Steering Group.
- Plans to broaden our collaboration...