



**SarcomaUK**  
The bone & soft tissue  
cancer charity

[sarcoma.org.uk](http://sarcoma.org.uk)

# National Sarcoma Survey 2020

## Awareness and diagnosis data

**Technical Report**



# Contents

1. Background .....	3
2. Responses.....	4
2.1. Response rate .....	4
2.2. Respondent characteristics .....	4
Sarcoma type.....	4
Location .....	5
Gender .....	7
Age.....	9
3. Results – 16+ Questionnaire .....	11
3.1. Diagnosis.....	11
Sarcoma awareness .....	11
Main symptoms experienced .....	12
Time before seeing a healthcare professional.....	13
Outcome of initial visit to a healthcare professional.....	13
Mention of sarcoma at initial appointment .....	14
Number of visits before referral.....	14
Starting treatment for another disease.....	15
Timeframe for diagnosis .....	16
How diagnosis was delivered.....	17
Explanation of diagnosis .....	17
Information at diagnosis.....	18
4. Further analysis .....	19
4.1. Results of Family and Carers Questionnaire.....	19
4.2. Results of Parents of Under 16s Questionnaire .....	19
4.3. Additional breakdown analysis .....	20
Age.....	20
Gender .....	23
Sarcoma Type.....	24
4.4. Additional cross tabulations analysis.....	26
4.5. Thematic analysis.....	27
Is there anything else you would like to say about your journey to being diagnosed? (Q9 16+ Questionnaire) .....	28
Is there anything else you would like to say about your child's journey to being diagnosed? (Q9 Parents of Under 16s Questionnaire) .....	29
5. Conclusions .....	30

# 1. Background

Sarcoma UK worked with Quality Health to collect data on sarcoma patient experience in order to build an evidence-base for influencing.

**This shorter report details the survey results relating to diagnosis and awareness. The full survey report will be released in July 2020.**

The survey consisted of three questionnaires to capture the experiences of a range of people affected by sarcoma: a 16+ questionnaire, a parents of under 16s' questionnaire, and a family and carers' questionnaire. These were designed and developed in October and November 2019. This involved a detailed process of drafting, reviewing, testing and revising the questions. Quality Health worked closely with Sarcoma UK on designing and agreeing the final question set.

The survey was accessible via an anonymous, online link, and was promoted via Sarcoma UK's networks and on social media. In order to maximise participation and ensure a high number of responses, people affected by any type of sarcoma were eligible to respond, and the combination of the 16+ and parents' questionnaires welcomed the experiences of people of all ages with sarcoma.

As the survey used a non-probability sample (as respondents were self-selecting), it is not possible to perform statistical tests on the data. However, the high overall response rate achieved means that a robust data set has been gathered and meaningful conclusions can be drawn.

The fieldwork was undertaken between 2 December 2019 (initial send out date) and 3 February 2020 (close date). The respondents were able to complete the questionnaire online, or over the phone if they preferred, and there were helpline and language line facilities available throughout the fieldwork.

## 2. Responses

### 2.1. Response rate

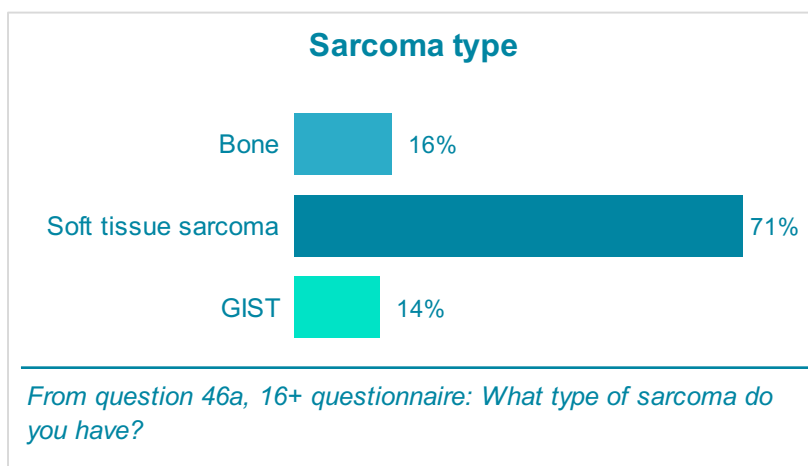
The number of responses for each of the questionnaires was as follows:

Adult	661
Parents of Under 16s	56
Family and Carers	400
<b>Total</b>	<b>1,117</b>

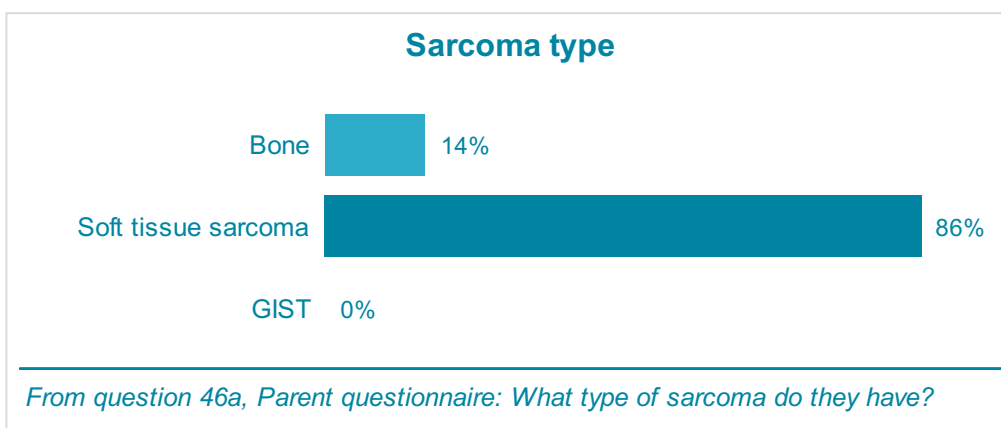
### 2.2. Respondent characteristics

#### Sarcoma type

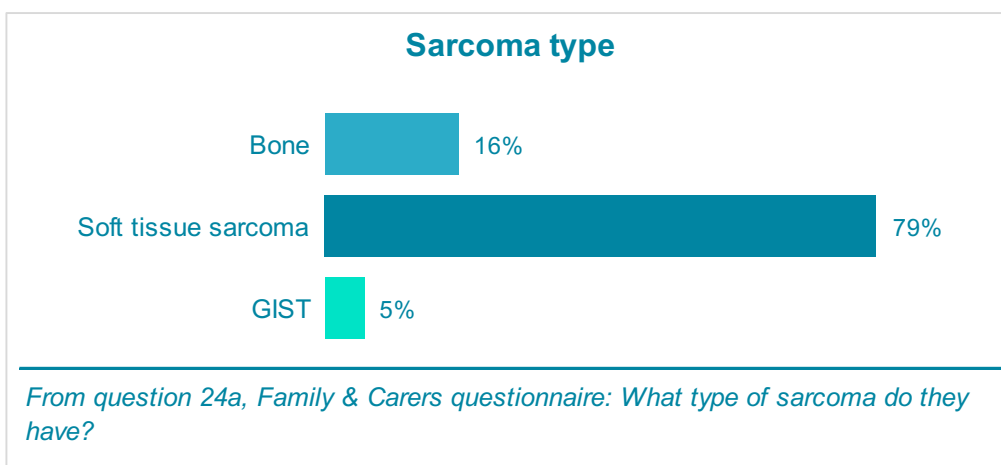
For the 16+ questionnaire, 71% of respondents said they have soft tissue sarcoma, 16% said they have bone sarcoma and 14% said they have GIST. (24 people did not answer this question.)



For the parents of under 16s questionnaire, 86% of respondents said their child has soft tissue sarcoma, and 14% said their child has bone sarcoma.

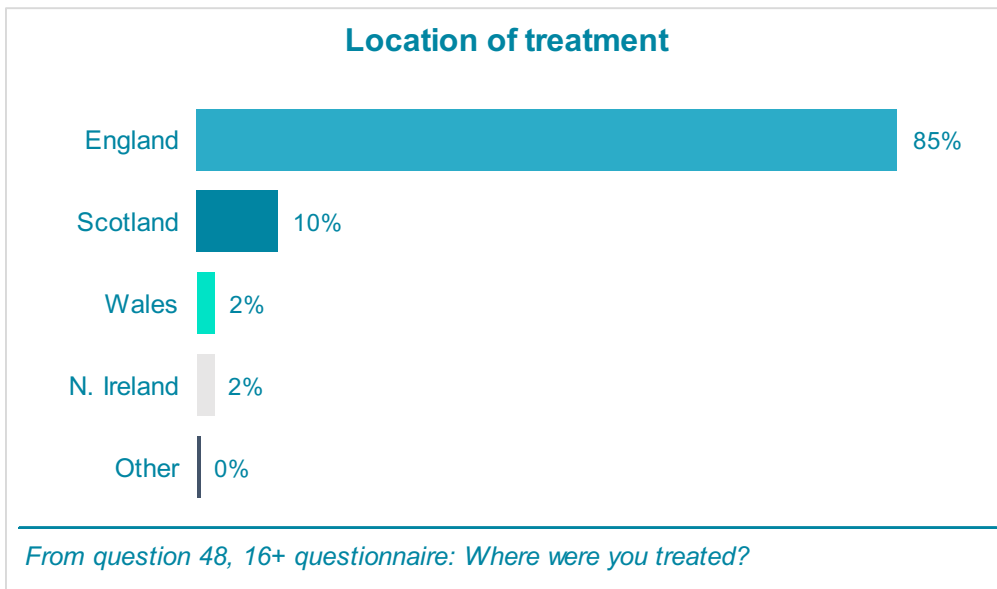


For the family and carers questionnaire, 79% of respondents said their family member or friend has soft tissue sarcoma, 16% said their family member or friend has bone sarcoma, and 5% said their family member or friend has GIST. (20 people did not answer this question.)

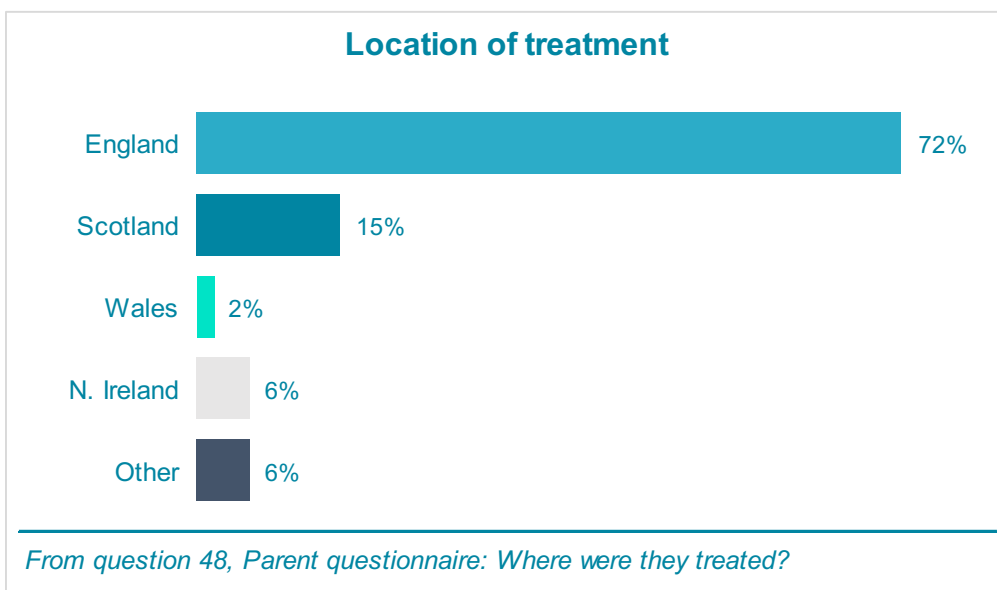


## Location

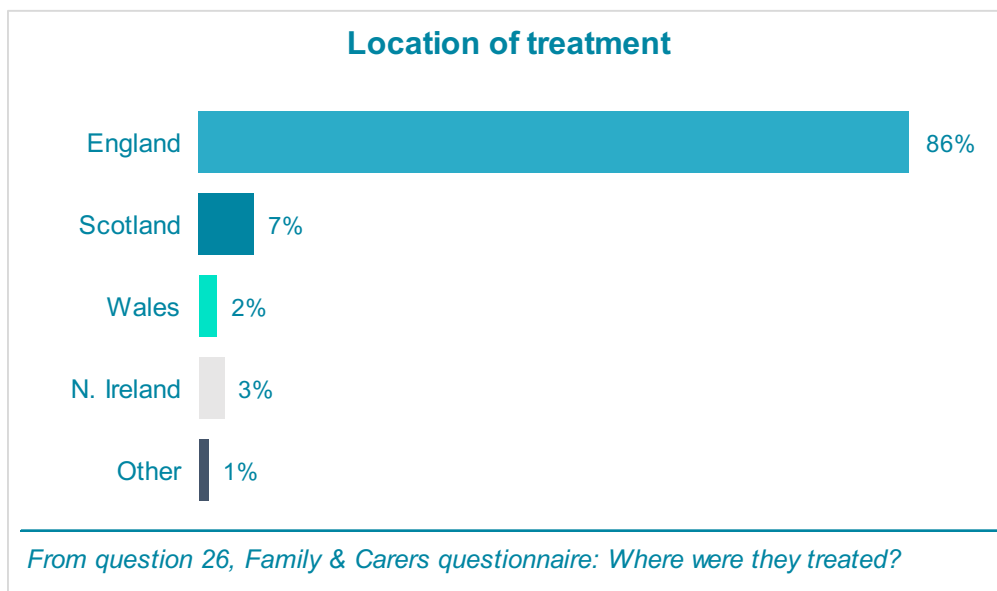
For the 16+ questionnaire, 85% of respondents said they were treated in England, 10% said they were treated in Scotland, 2% said they were treated in Wales, 2% said they were treated in Northern Ireland, and 0% (3 respondents) chose 'other'. (16 people did not answer this question.)



For the parents of under 16s questionnaire, 72% of respondents said their child was treated in England, 15% said their child was treated in Scotland, 6% said their child was treated in Northern Ireland, 2% said their child was treated in Wales, and 6% chose 'other'. (2 people did not answer this question.)

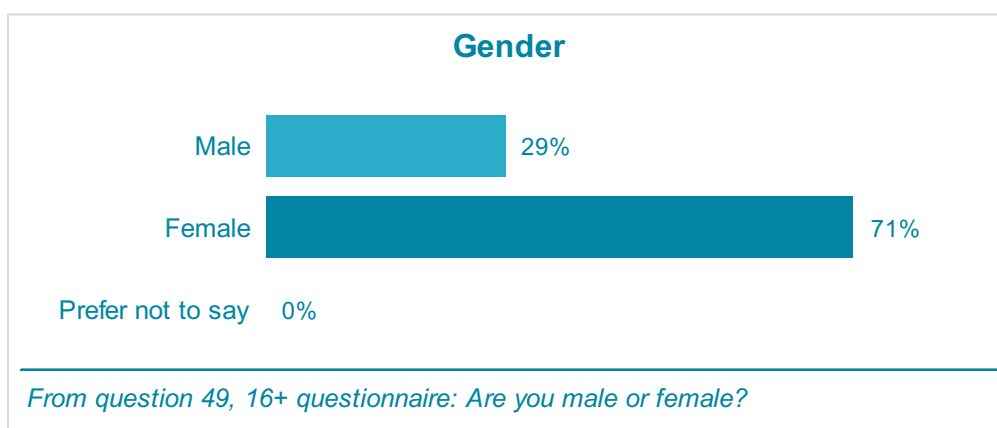


For the family and carers questionnaire, 86% of respondents said their family member or friend was treated in England, 7% said their family member or friend was treated in Scotland, 3% said their family member or friend was treated in Northern Ireland, 2% said their family member or friend was treated in Wales, and 1% chose 'other'. (16 people did not answer this question.)

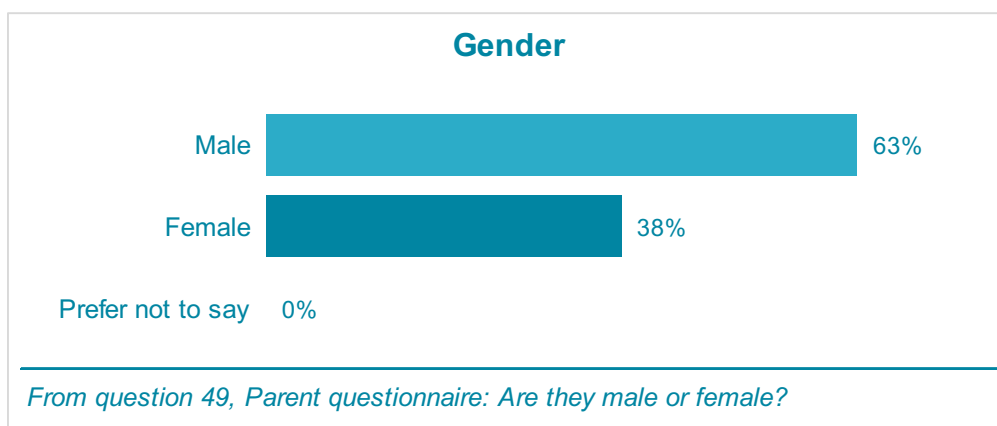


## Gender

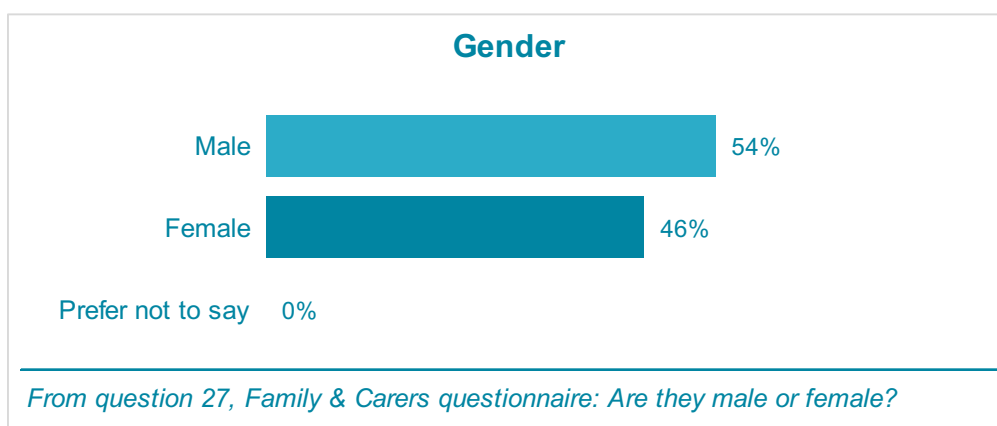
For the 16+ questionnaire, 71% said they are female and 29% said they are male. (6 people did not answer this question.)



For the parents of under 16s questionnaire, 63% of respondents said their child is male and 38% said their child is female.



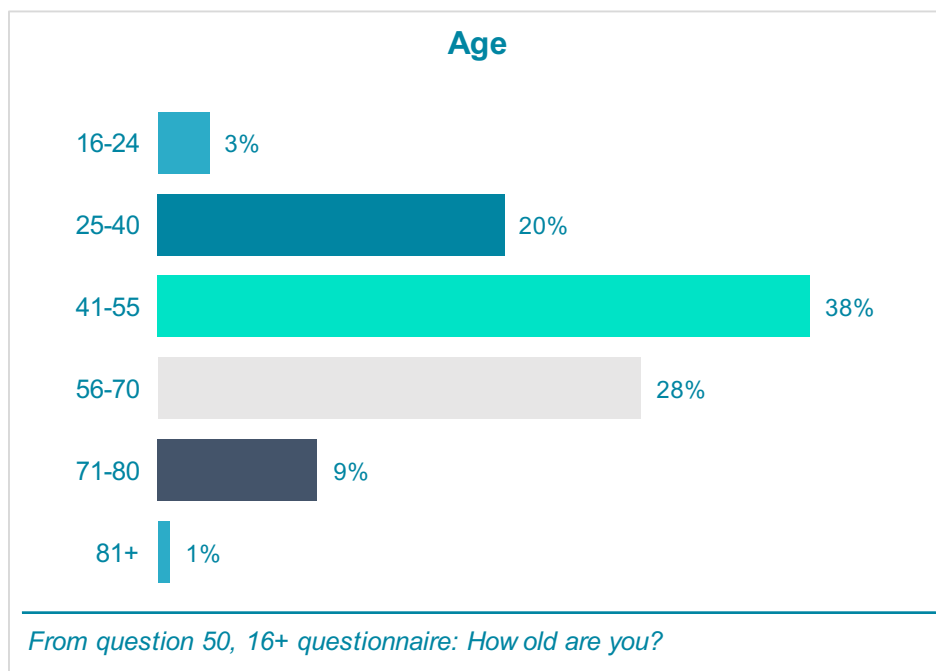
For the family and carers questionnaire, 54% of respondents said their family member or friend is male, and 46% said their family member or friend is female. (6 people did not answer this question).



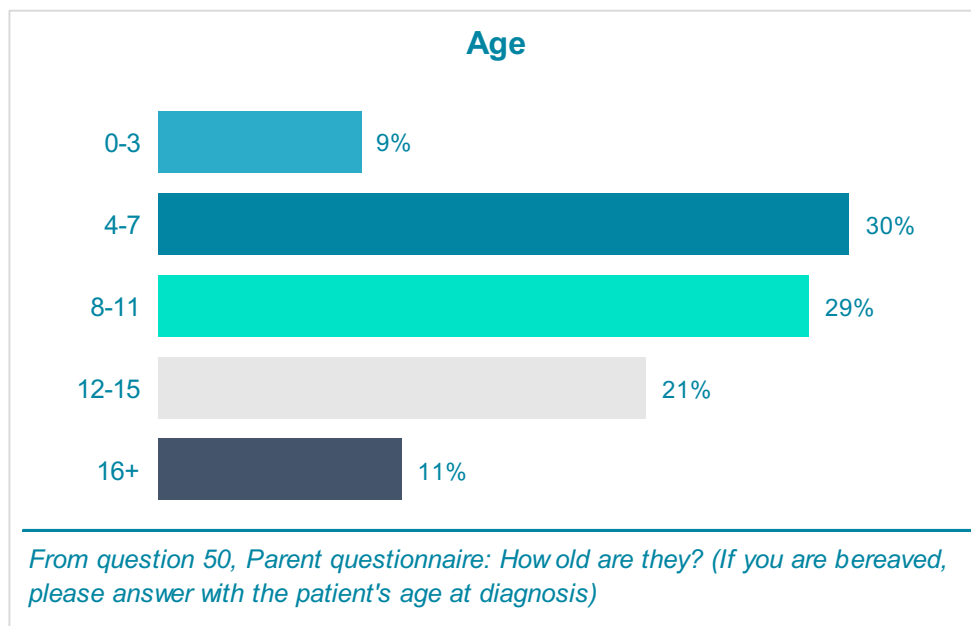


## Age

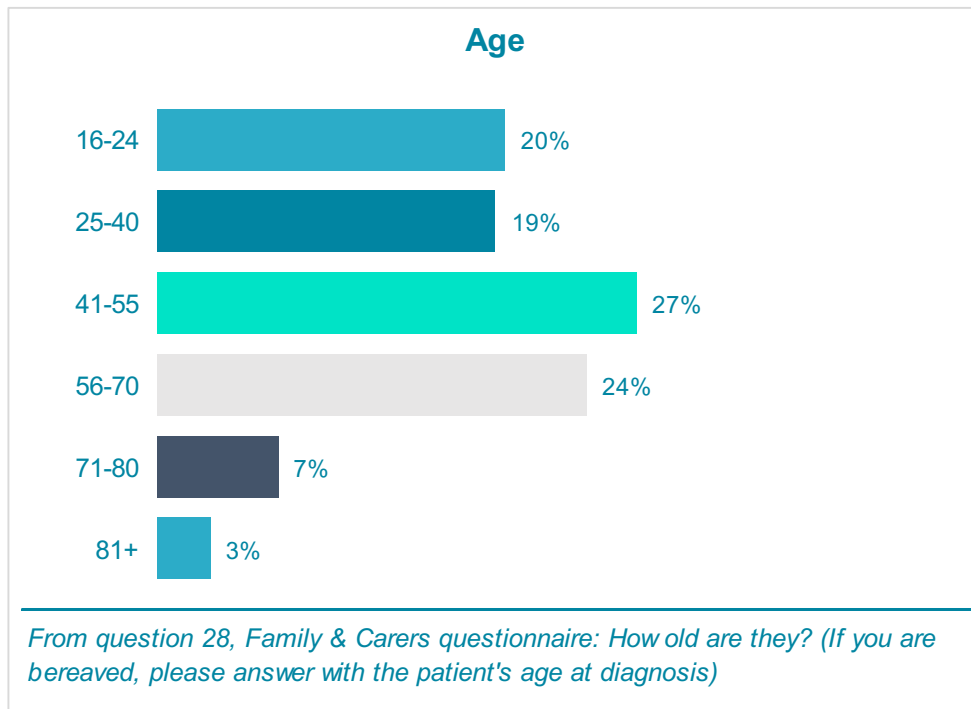
For the 16+ questionnaire, 3% of respondents said they were 16-24, 20% were 25-40, 38% were 41-55, 28% were 56-70, 9% were 71-80 and 1% were 81+. (1 person did not answer this question.)



For the parents of under 16s questionnaire, 9% of respondents said their child is 0-3, 30% were 4-7, 29% were 8-11, 21% were 12-15 and 11% were 16+.



For the family and carers questionnaire, 20% of respondents said their family member or friend is 16-24, 19% were 25-40, 27% were 41-55, 24% were 56-70, 7% were 71-80 and 3% were 81+. (8 people did not answer this question.)

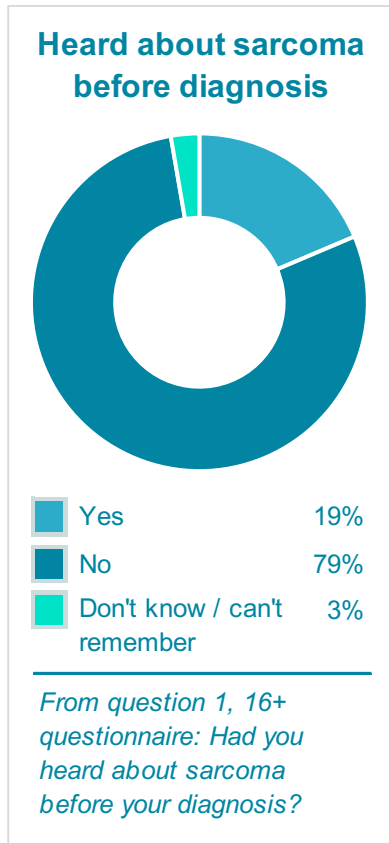


### 3. Results – 16+ Questionnaire

#### 3.1. Diagnosis

##### Sarcoma awareness

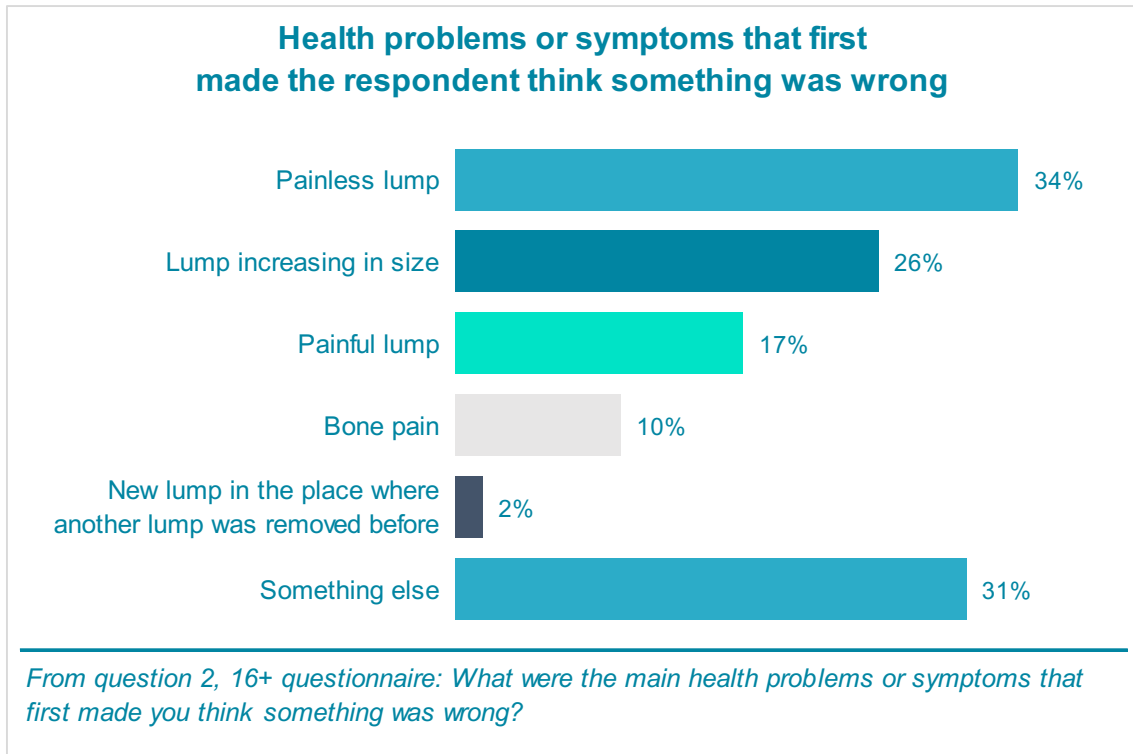
**19%** of respondents had heard of sarcoma before their diagnosis.  
(Q1, 16+ Questionnaire)



Also, around a fifth (**21%**) of the family and carers had heard of sarcoma before their family member / friend was diagnosed. (Q1 Family & Carers Questionnaire)

## Main symptoms experienced

When asked what were the main health problems or symptoms that first made people think something was wrong – of the symptoms listed, a painless lump was the most common (**34%**), followed by a lump increasing in size (**26%**), a painful lump (**17%**), bone pain (**10%**) and a new lump in the place where another lump was removed before (**2%**). (Q2, 16+ Questionnaire)



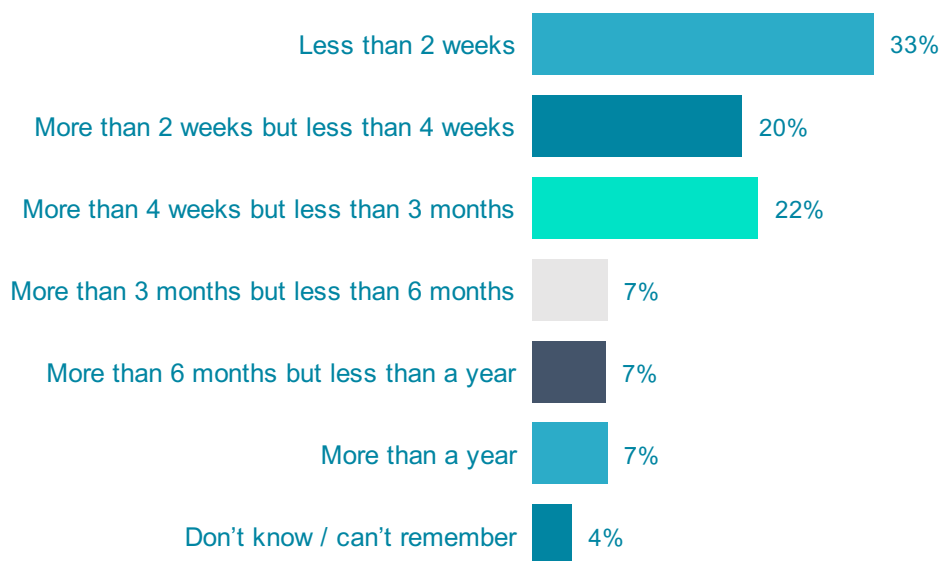
In addition, when the family and carers were asked if their family member / friend had mentioned they had problems or symptoms, the most common choices, again, were a lump increasing in size (**30%**) and a painless lump (**27%**). (Q3 Family & Carers Questionnaire)

## Time before seeing a healthcare professional

Nearly a third of respondents (**33%**) said it was less than two weeks between thinking something might be wrong with them and first visiting a GP, nurse or going to A&E. **20%** said it was between 2 and 4 weeks, and a further **22%** said between 4 weeks and 3 months.

(Q3, 16+ Questionnaire)

### Time between patient first thinking something might be wrong and first appointment with a GP/Nurse or visit to A&E



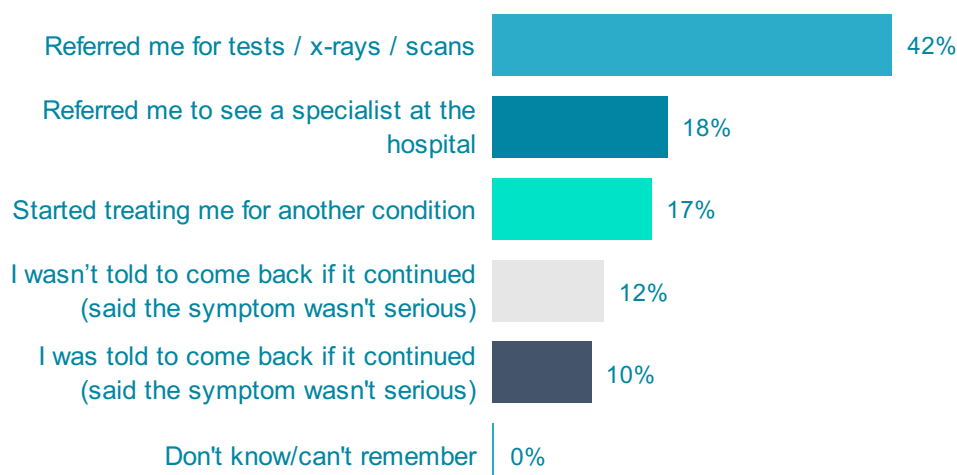
From question 3, 16+ questionnaire: How long was it from the time you first thought something might be wrong with you until you first saw a GP, Nurse or went to A&E?

## Outcome of initial visit to a healthcare professional

Nearly half (**42%**) said this healthcare professional referred them for tests / x-rays / scans. A further **18%** were referred to see a specialist at the hospital. **17%** started treatment for another condition, **12%** were told to come back if it continued and **10%** were told not to come back if it continued.

(Q5, 16+ Questionnaire)

### What the healthcare professional first seen about main health problems or symptoms said/did

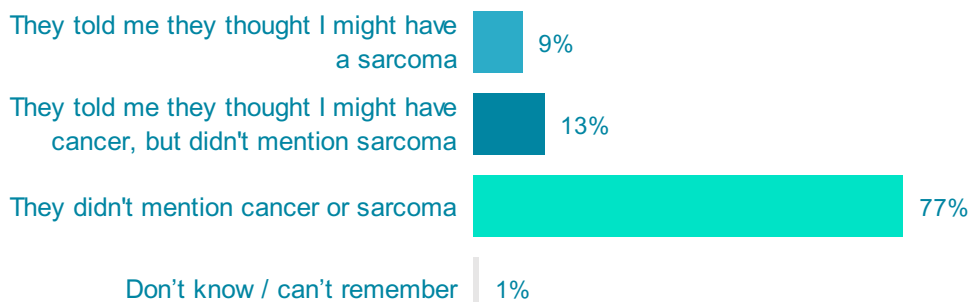


From question 5, 16+ questionnaire: What did this healthcare professional say / do?

## Mention of sarcoma at initial appointment

Of the respondents who were referred for further tests or to see a specialist, most (77%) said that sarcoma or cancer wasn't mentioned at this stage. 9% reported that the healthcare professional said they might have sarcoma and 13% said the healthcare professional told them they might have cancer but did not mention sarcoma. (Q6, 16+ Questionnaire)

### Specific reference to sarcoma during healthcare professional's diagnosis

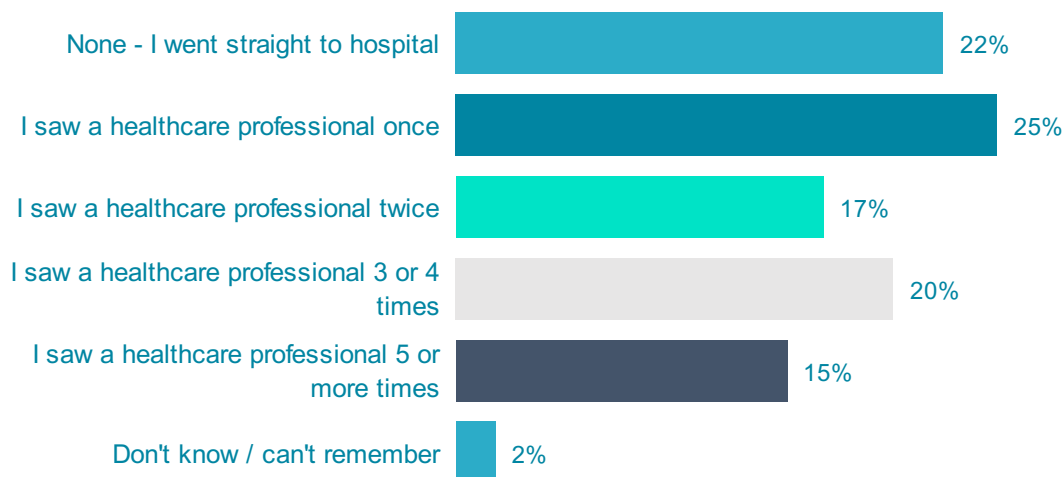


From question 6, 16+ questionnaire: Did the healthcare professional tell you that they thought you might have a sarcoma?

## Number of visits before referral

Respondents were fairly evenly distributed in the amount of times they saw a healthcare professional before being referred for further tests. 25% saw a healthcare professional once, while 15% saw a healthcare professional five or more times. (Q7, 16+ Questionnaire)

### How many times the patient saw a healthcare professional about their symptoms prior to referral for further tests



From question 7, 16+ questionnaire: Before you were referred for further tests, how many times did you see a healthcare professional about the symptoms you had?

Analysis confirmed that those who saw a healthcare professional more times before being referred were more likely to say that their overall mental health / emotional wellbeing had been negatively affected (C4). Please see 5.4 for all additional cross tabulation analysis.

## Starting treatment for another disease

Nearly a quarter (23%) of respondents that they had started treatment for another disease. (Q10, 16+ Questionnaire)

Respondents were invited to specify what disease. This included comments such as:

*'I was on the list to have ovarian surgery but, days before, I was told it was sarcoma.'*

*'Kidney infection.'*

*'They were treating a lump as potentially breast cancer.'*

*'Fibroadenoma.'*

*'I was repeatedly given antibiotics for an infected cyst. I then had day surgery to remove the cyst. They removed the part of the tumour that was visible.'*

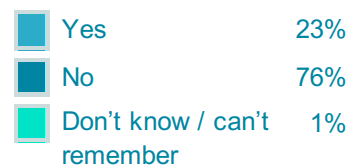
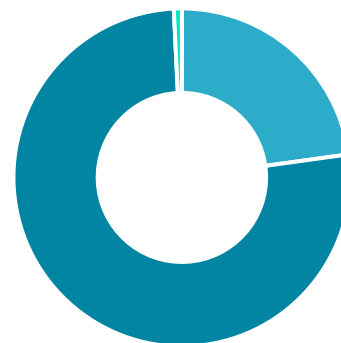
*'Not disease but GP attempted to aspirate my "ganglion" to then find out it was a solid mass.'*

*'Told to take paracetamol for a sprained foot.'*

*'Lump was diagnosed as cyst benign.'*

*'Iron tablets for anaemia.'*

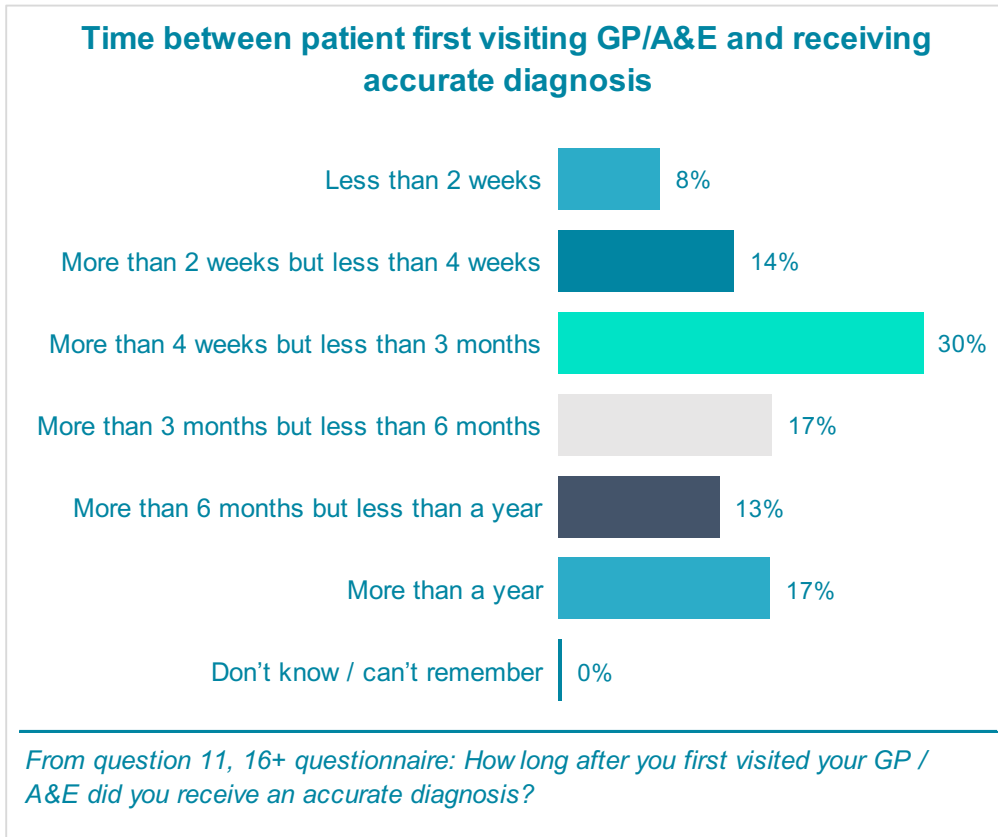
### Patient started treatment for another disease



From question 10, 16+ questionnaire: Did you start treatment for another disease?

## Timeframe for diagnosis

When asked how long after first visiting a healthcare professional people received an accurate diagnosis, the most popular choice was more than four weeks but less than three months (**30%**). (Q11, 16+ Questionnaire)



Analysis confirmed that more than half of those who waited for more than a year for an accurate diagnosis, had to see a healthcare professional five or more times (D1). It also showed that the length of time to receive an accurate diagnosis did not affect the extent to which people's overall mental health and emotional wellbeing is negatively affected. Please see 5.4 for all additional cross tabulation analysis.



## How diagnosis was delivered

The majority of respondents (79%) received their diagnosis from a consultant. 6% were told by a GP, 5% were told by a nurse and 2% got a clinic letter. (Q12, 16+ Questionnaire)

9% chose 'other'. This included comments such as:

'Got clinic text message.'

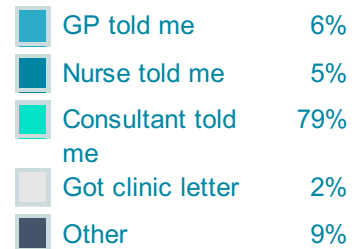
'Read it in patient portal. I was originally told it was benign.'

'Phone call from consultant secretary!'

'After an MRI.'

'Surgeon who removed the tumour told me.'

### Source of first communication about sarcoma diagnosis

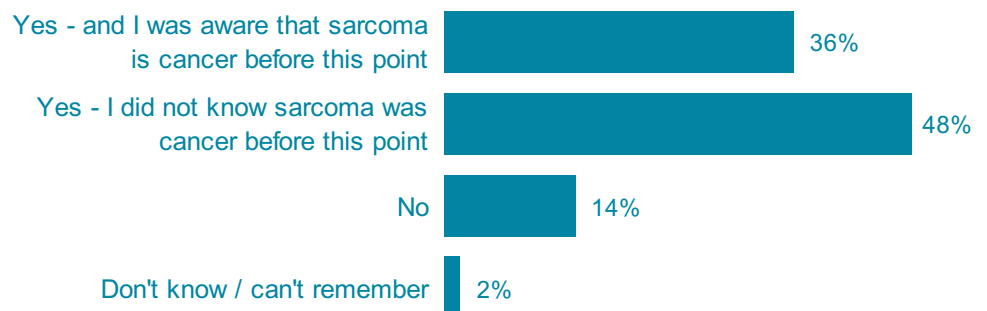


From question 12, 16+ questionnaire: How did you learn about your sarcoma diagnosis?

## Explanation of diagnosis

At the point of receiving their diagnosis, 14% said that it was **not** explained that sarcoma is a cancer. 36% said it was explained but they **already knew** sarcoma was a cancer, and 48% said it was explained and they **did not know before** this. (Q13, 16+ Questionnaire)

### Whether it was explained that sarcoma was a cancer upon receiving diagnosis



From question 13, 16+ questionnaire: When you received your diagnosis, was it explained that sarcoma is a cancer?

## Information at diagnosis

**39%** of people said they received no information at diagnosis. Around a third (**37%**) said they were given information from a charity, and **14%** said they were given an information sheet from hospital.  
(Q14a, 16+ Questionnaire)

**11%** chose 'other'. This included comments such as:

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*'The diagnosis was given over the phone by the specialist. They asked me if I had any questions. They were very detailed and did their best to answer my questions. They were very honest and realistic.'*

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*'Detailed explanation from an experienced and leading sarcoma surgeon.'*

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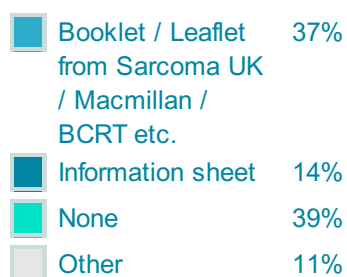


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*'Printed Google search.'*

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### Information given at diagnosis

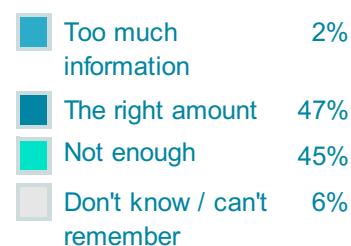
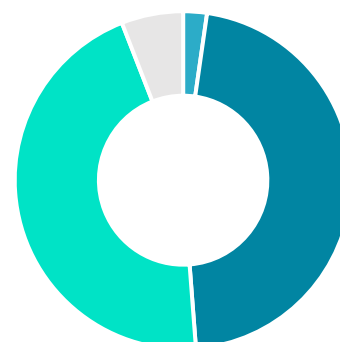


*From question 14a, 16+ questionnaire: At diagnosis, what sort of information were you given?*

Very few respondents (**2%**) said that they received too much information at diagnosis. Just under half (**47%**) said they got the right amount, and **45%** said they didn't get enough.

(Q14b, 16+ Questionnaire)

### Amount of information given at diagnosis



*From question 14b, 16+ questionnaire: At diagnosis, how much information were you given?*

## 4. Further analysis

### 4.1. Results of Family and Carers Questionnaire

There were 412 responses to the family and carers survey. People who are caring for a friend or family member who has sarcoma – or friends or family of people who had passed away with sarcoma – were invited to complete the survey. The survey contained some different questions to the main survey, which asked about the impact on the carer as well as the patient. Carers or friends may look after partners or spouses, other relatives, friends or neighbours, and many who would not consider themselves as a carer may find themselves taking on this role.

There were some clear key points arising from the data:

- Q1 Only one-fifth (21%) had heard of sarcoma before their friend/family member was diagnosed.
- Q5 Only half (49%) knew that sarcoma was a type of cancer.
- Q6 Two-thirds (67%) found out about sarcoma online

### 4.2. Results of Parents of Under 16s Questionnaire

There were 56 responses from parents of children under the age of 16. Parents were contacted through Sarcoma UK's networks and were encouraged to complete the survey on behalf of their children and, if appropriate, with their children (for the older age groups).

Because the number of responses is lower (when compared to the patient survey that makes up the main body of this report, and the family and carers survey above) they should be treated with caution. However, there are interesting findings from this group which correspond to the findings in the other categories:

- Q1 Three-quarters (75%) of parents had not heard of sarcoma before their child's diagnosis.
- Q7 Nearly a half (48%) of parents saw a health professional with their child more than 3 times before they were referred for more tests.
- Q13 59% of parents did not know that sarcoma was a cancer until it was explained at their child's diagnosis.
- Q14b Nearly one-third of parents (29%) said they were not given enough information when their child was diagnosed.

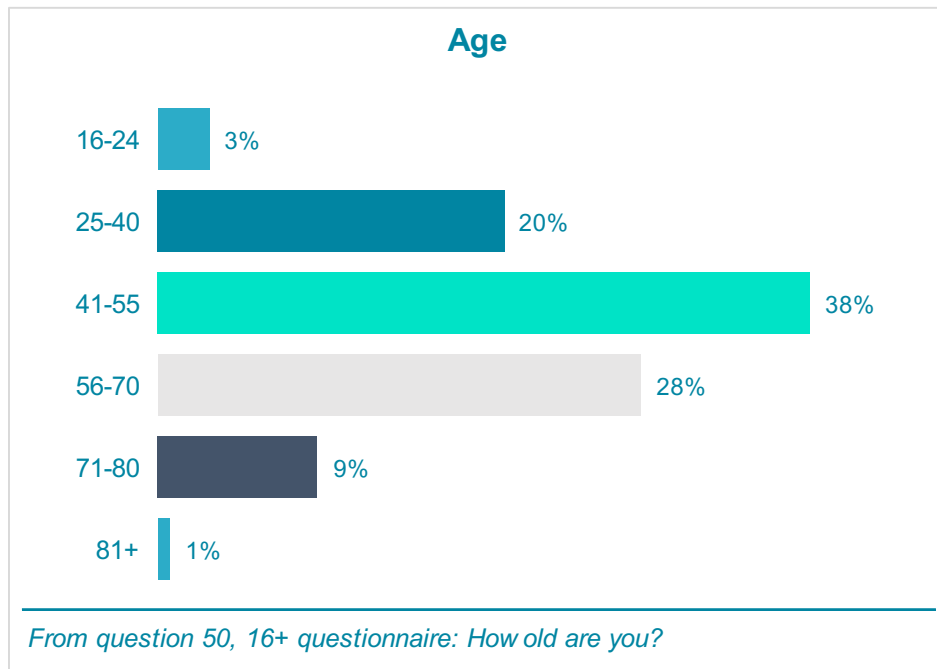
### 4.3. Additional breakdown analysis

As part of the analysis, Quality Health broke down the data according to key variables to identify differences in experience and opinion, as well as to identify areas where specific groups may be in particular need of support. The areas for which further analysis have been provided are:

- Age
- Gender
- Sarcoma type
- Location

In addition to these, a number of cross tabulations were carried out which looked at specific issues or hypotheses, and a summary of some of the key findings from this is also included in this section of the report.

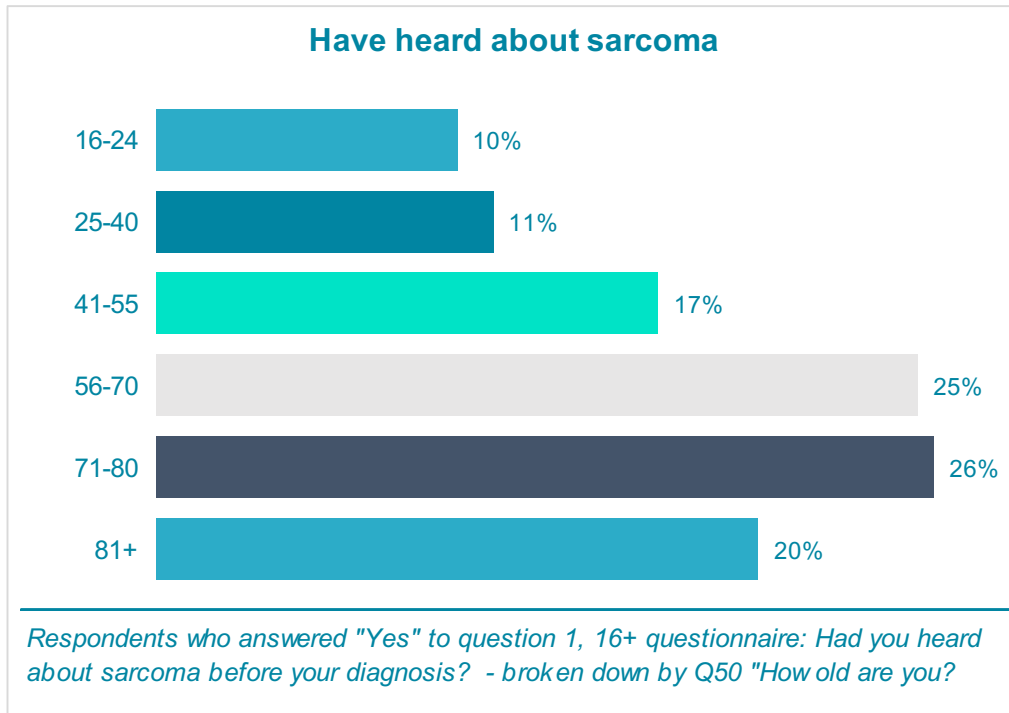
#### Age



The numbers are relatively small for some age groups (16-24s and 81+) so, when making comparisons, these must be treated with caution. There are some clear differences between the age groups, and these are in line with other surveys (carried out by Quality Health). In general, older people reported that they were more satisfied, particularly with the level of support and information they received. Older people were also less likely to report a negative emotional impact. There are a number of reasons for this which should be considered, including whether older people's expectations are lower than that of younger generations, and whether older people find it harder to be critical of professionals caring for them or the service they receive. It is also worth considering how technology and access to information has impacted on younger people's expectations and how this affects the feedback they give.

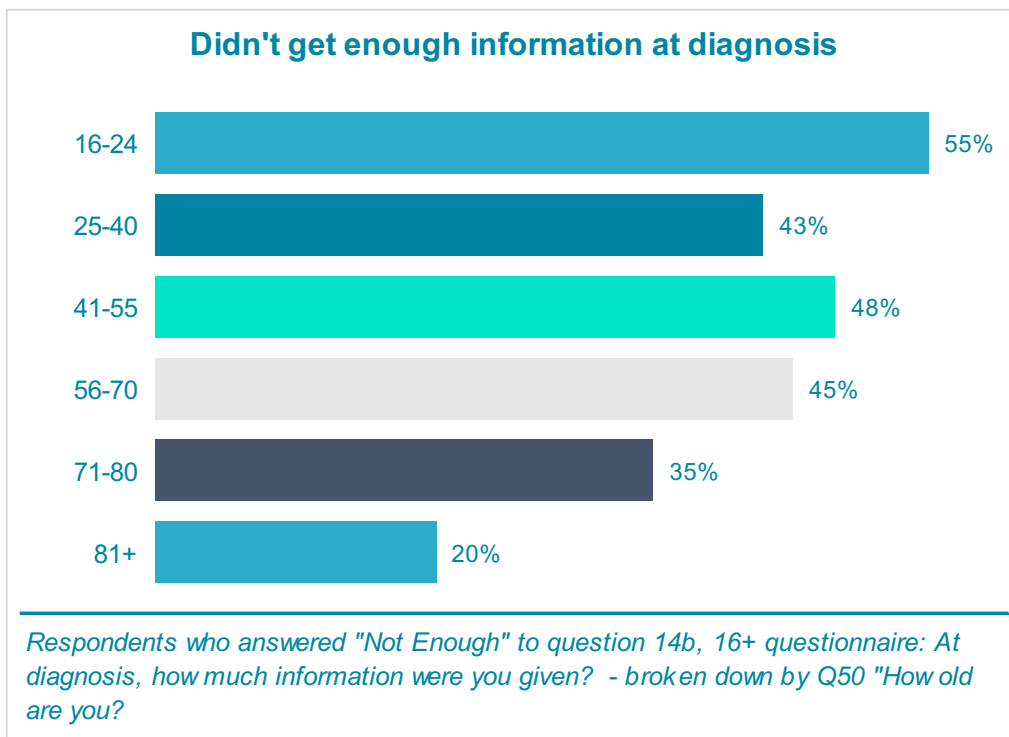
Some of the key findings include:

- **Q1 The older people are, the more likely they were to have heard of sarcoma (one-quarter of those aged over 56; compared to one-tenth of those aged between 16 and 40).**



- Q2 Older people were less likely to cite bone pain as the main symptom that made them think something was wrong (6% of those aged 56+; compared to 16% of those aged between 16 and 40).
- Q7 Young people were more likely to see a healthcare professional 5 or more times before being referred for further tests. More than a third (35%) of 16-24 year olds had to see a healthcare professional 5 or more times, compared to 8% of 71-80 year olds.
- Q10 Older people were less likely to have started treatment for something else (35% of 16-24 year olds, compared to 17% of 71-80 year olds).

- **Q14b Younger people were more likely to say they didn't get enough information at diagnosis (55% of 16-24 year olds, compared to 35% of 71-80 year olds).**



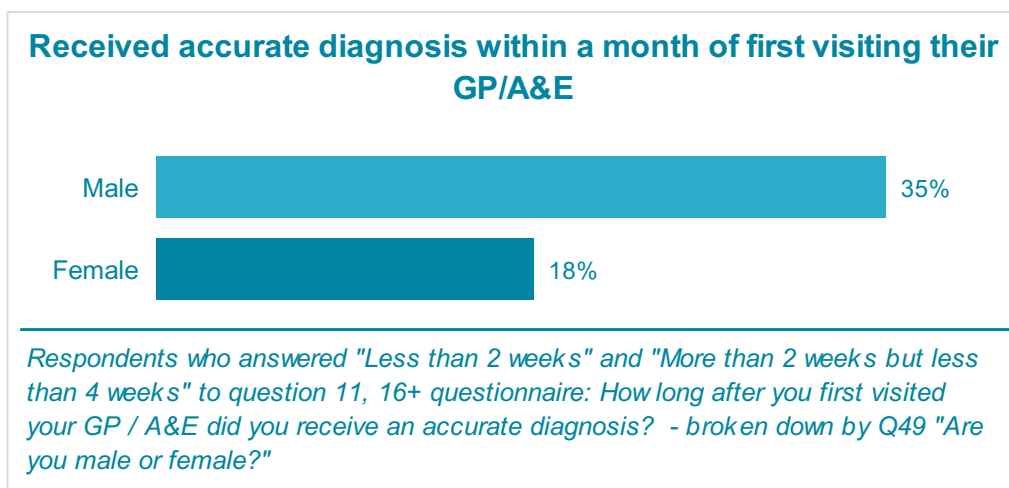
- **Q26 Younger people were less likely to say they have had a CNS in charge of their care at any time (55% of 16-24 year olds, compared to 65% and 63% of 41-55 year olds and 56-70 year olds respectively).**
- **Q28 The oldest age group were more likely to say they were given enough information to help make decisions about their treatment and care (65%-67% of those aged between 16 and 70, compared to 76% of those aged over 71).**

## Gender

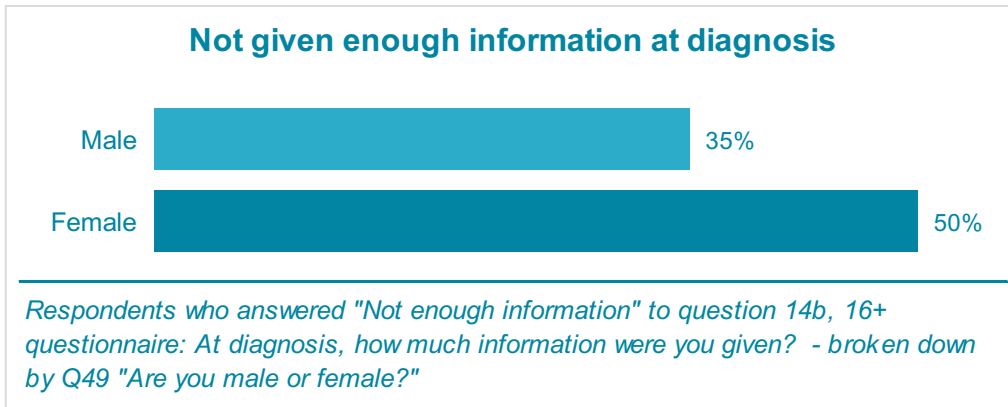
Generally, women were less satisfied with the amount of information and support that they were given. Women answered more negatively around some elements of their diagnosis experience, particularly the time it took to get an accurate diagnosis.

It is important to consider the results here in terms of what this may be telling us over and above simple differences between men and women – for example: whether there are differences in expectations of men and women; how easy men and women find it to talk about, or admit to having emotional support needs; and whether men and women are treated differently by professionals.

- Q6 More women than men said the healthcare professional they saw first didn't mention cancer or sarcoma (80% women, compared to 72% men).
- Q7 It was more common for men than women to go straight to hospital (30% men, compared to 19% women).
- **Q11 A higher percentage of men received an accurate diagnosis within a month of first visiting their GP/A&E (35% men, compared to 18% women).**

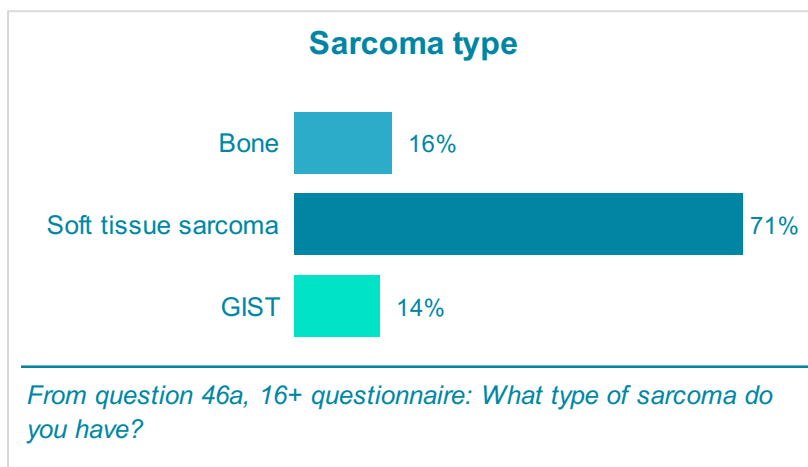


- **Q14b Women were more likely to say they were not given enough information at diagnosis (50% women, compared to 35% men).**



- **Q25 Women were more likely to say they were not given a written care plan (58% women, compared to 46% men).**

## Sarcoma Type

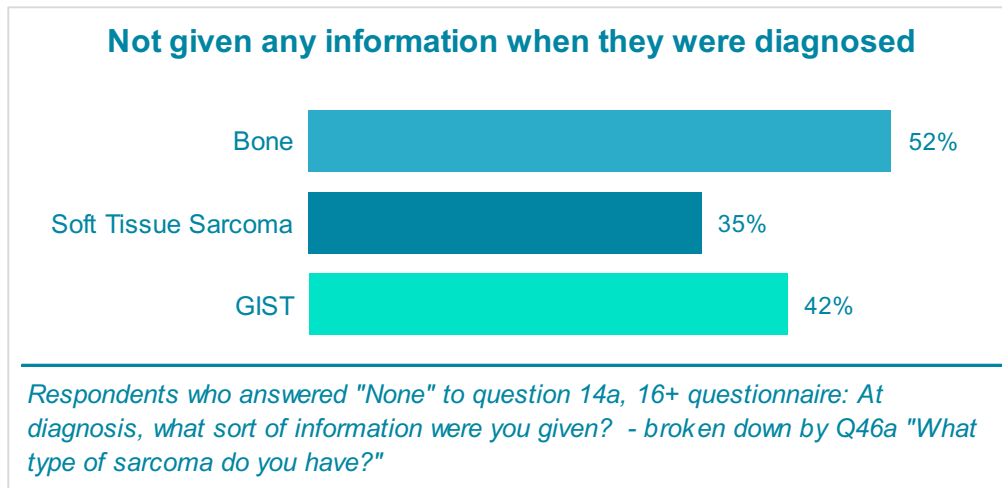


The breakdown by sarcoma type provides detail on the differences between experiences of patients with different types of sarcoma, and enables some comparisons to be drawn. The data shows a mixed picture, with bone sarcoma patients experiencing longer waits for diagnosis and being less likely to say they do not have the information they need; while GIST patients were the least likely to say they were offered the emotional support they need, but more likely to have a written care plan.

- **Q3 GIST patients were most likely to see a doctor within 2 weeks of thinking that something might be wrong with them (55%) while bone sarcoma patients were least likely (19%).**



- Q5 Bone sarcoma patients were most likely to be told that symptoms weren't serious and that they should come back if symptoms persisted (18%, compared to 10% soft tissue and 5% GIST).
- Q11 Bone and soft tissue sarcoma patients were more likely to wait longer for an accurate diagnosis (20% and 18% respectively, waited more than a year).
- **Q14a Bone sarcoma patients were more likely to say they were not given any information when they were diagnosed (52%).**



- Q14b GIST patients were more likely to say they had not been given enough information at diagnosis (51%) although the number was also high for both bone (43%) and soft tissue (44%) patients.
- Q31 Bone and soft tissue sarcoma patients were more likely to say that their mental health/wellbeing had been affected by their diagnosis and treatment (24% and 28% respectively said 'severely', compared to 9% GIST).

## 4.4. Additional cross tabulations analysis

As a further part of the analysis, a number of cross tabulations were examined to establish whether there was a relationship between particular variables and answers given. In order to do this, Sarcoma UK provided a number of hypotheses or theories to explore. It is important to note that the analyses carried out were not statistical tests but were looking to see if there were trends in the data which add further evidence to the findings from the breakdown analysis.

We have also included any analysis that has shown where there is not a clear relationship being shown in the survey data, which in itself can provide some interesting insights - for example, into assumptions about the impact of a diagnosis on different groups.

Finally, we have noted where we are unable to draw any meaningful conclusions because the numbers are too small.

### 1. The impact on those who had to see a healthcare professional more times before being referred

Analysis showed that those who saw a healthcare professional once before being referred were more likely to have an operation and/or radiotherapy than those who saw a healthcare professional more times.

The analysis also showed that those who saw a healthcare professional more times were more likely to say that their overall mental health / emotional wellbeing had been negatively affected.

The analysis also looked at whether there was a correlation between how many times someone had seen a healthcare professional and how their day to day life was impacted once treatment was stopped. However, there were no clear findings emerging from this.

### 2. The impact of waiting longer to receive an accurate diagnosis

The analysis showed that those who waited longer to receive an accurate diagnosis were more likely to have had more than one operation. It also showed that the length of time to receive an accurate diagnosis did not affect the extent to which people's overall mental health and emotional wellbeing is negatively affected.

There was some correlation between the length of time to receive an accurate diagnosis and the likelihood that someone is affected by a number of factors (such as coping with side effects, disability or reduced mobility). However, there were some small numbers here and this was not true for those people who had waited over a year.

## 4.5. Thematic analysis

This summary presents the findings following a thematic analysis of the free text comments. In order for Sarcoma UK to understand and identify the main issues contained within these comments, Quality Health undertook a systematic analysis. All comments were read in full, and an appropriate code applied to each one. During this process, Quality Health categorised the comments by the themes which they address. Many of the comments were coded more than once if they addressed more than one theme. This means the total number of 'individual' comments exceeds the number of 'full' comments.

### **Is there anything else you would like to say about your (child's) journey to being diagnosed? (Q9 16+ Questionnaire) (Q9 Parents of Under 16s Questionnaire)**

In order for Sarcoma UK to understand and identify the main issues contained within these comments, Quality Health undertook a systematic analysis of the comments by theme. The themes arising from the comments are listed below:

- **Time before being referred** Comments about the time people waited before being referred for further tests.
- **Accuracy of diagnosis** Comments about the accuracy of the diagnosis people received, often about misdiagnosis.
- **Being taken seriously / listened to** Comments about medical professionals taking people's symptoms seriously, or not.
- **Time for diagnosis** General comments about the length of time to receive diagnosis.
- **General experience** Comments about the quality of experience, often about opinions of medical professionals.
- **Waiting times / speed of system** Comments about the speed of the system, for example, the time after being referred before being seen, or time to receive results.
- **Chance diagnoses and missed opportunities** Comments about people that were diagnosed by chance or felt there were missed opportunities to diagnose them – for example, at scans for other conditions.
- **Number of visits / people involved** Comments about seeing multiple medical professionals, going back for multiple tests, etc.
- **Impact of diagnosis speed / accuracy** Comments about how diagnosis experience affected outcomes i.e. a slow diagnosis leading sarcoma to metastasise.
- **Communication / information** Comments about communication of diagnosis, information shared, contact from medical professionals, etc.
- **Awareness of / familiarity with sarcoma** Comments about (mainly medical professionals') knowledge of or familiarity with sarcoma.
- **Personal details** Factual comments about respondents' diagnosis, for example, how long ago, or where they were treated.
- **Private care** Comments that refer to private care.

## Is there anything else you would like to say about your journey to being diagnosed? (Q9 16+ Questionnaire)

There were **455** comments received for the 16+ questionnaire. Of the 455 full comments, **981** individual comments were identified.

Theme	Count	Percentage
Time before being referred	117	12%
Accuracy of diagnosis	117	12%
Being taken seriously / listened to	113	12%
Time for diagnosis	103	10%
General experience	98	10%
Waiting times / speed of system	93	9%
Chance diagnoses and missed opportunities	54	6%
Number of visits / people involved	52	5%
Impact of diagnosis speed / accuracy	51	5%
Communication / information	50	5%
Awareness of / familiarity with sarcoma	49	5%
Personal details	48	5%
Private care	36	4%
<b>Total</b>	<b>981</b>	<b>100%</b>

### Time before being referred

*'It was far too slow a process and when I was eventually sent for an MRI, it was months after seeing my GP. The MRI showed I had a sarcoma.'*

*'Disappointed I wasn't scanned earlier in the process. From initial GP check, where told to only come back if it gets bigger, to the point of the ultrasound scan which diagnosed the cancer, months elapsed.'*

### Accuracy of diagnosis

*'Treated for something else - no tests done as considered too young for cancer!'*

*'I was misdiagnosed for six months.'*

### Being taken seriously / listened to

*'The GP said I was a hypochondriac and sent me away!'*

*'I was made to feel that I was wasting my GP's time. It was only after I moved and saw a new GP that my concerns were taken seriously and acted upon.'*

## Is there anything else you would like to say about your child’s journey to being diagnosed? (Q9 Parents of Under 16s Questionnaire)

There were **44** comments received for the parents’ questionnaire. Of the 44 full comments, **89** individual comments were identified.

Theme	Count	Percentage
Being taken seriously / listened to	17	19%
Time before being referred	12	13%
Accuracy of diagnosis	9	10%
Time for diagnosis	8	9%
Waiting times / speed of system	8	9%
Number of visits / people involved	8	9%
General experience	7	8%
Chance diagnoses and missed opportunities	7	8%
Awareness of / familiarity with sarcoma	4	4%
Impact of diagnosis speed / accuracy	4	4%
Personal details	3	3%
Private care	1	1%
Communication / information	1	1%
<b>Total</b>	<b>89</b>	<b>100%</b>

### Being taken seriously / listened to

*‘It was far too difficult to get someone to act with urgency. Had I not lost patience and refused to leave A&E until we saw a paediatrician, I don’t know what would’ve happened.’*

*‘My GP wouldn’t listen to me. I knew something was seriously wrong with my child.’*

### Time before being referred

*‘A&E doctors were all baffled and couldn’t understand why GP hadn’t referred them before now. They got us an appointment with specialist the following morning.’*

*‘My child was referred to hospital immediately by the GP and seen the next day. I felt let down by them as they told us for a month that it was something else before referring them for a scan, despite the fact that I was worried.’*

### Accuracy of diagnosis

*‘After a couple of trips to the GP, we were told that our child had a condition (not sarcoma) and were referred to a specialist. We waited weeks for this appointment and the specialist knew straight away that it was a tumour and sent us straight to the correct consultant at a different hospital.’*

*‘GP said growing pains. I self-referred, and GP adamant nothing wrong apart from growing pains.’*

## 5. Conclusions

Ahead of this survey, many people affected by sarcoma made it clear that their experience was not what it should have been. Now, this survey data from over 1,000 people provides a rich dataset that is clear in demonstrating that sarcoma patients are not getting access to the care and support they need.

Patients often took a long time before presenting at a primary care professional, and then faced a number of hurdles before being referred or receiving an accurate diagnosis. As a vast majority had not heard of sarcoma before their diagnosis, it is likely that patients did not recognise the signs and symptoms of sarcoma. In addition, many patients had to visit a healthcare professional many times with their symptoms before being referred for further tests, suggesting that GPs may not link the signs present to sarcoma either. Indeed, analysis of the free text comments showed that, when asked what the biggest improvements to sarcoma services would be, sarcoma awareness among medical professionals was one of the most popular choices.

Once referred into the system, patients experienced additional delays before receiving an accurate diagnosis. In the free text comments around diagnosis were a number of personal examples of how a slow diagnosis had led to worse outcomes for the individual. This unnecessarily long period between first symptoms and an accurate diagnosis is hugely concerning, as the sooner diagnosis takes place, the more likely a patient will be to have successful treatment.

This results of this survey of sarcoma patients and carers provide the rich and robust data needed to lobby governmental bodies to improve sarcoma service.