Sarcoma UK
The bone & soft tissue cancer charity

sarcoma.org.uk

# Impact of Sarcoma: National Sarcoma Survey 2020

## Technical Report

Quality Health

# Contents

# 1. Executive summary

## 1.1. About sarcoma and the survey

Sarcomas are uncommon cancers that can affect any part of the body, on the inside or outside, including the muscle, bone, tendons, blood vessels and fatty tissues. Sarcoma diagnoses make up about 1.4% of all cancer diagnoses in the UK, and 15 people are diagnosed with sarcoma every day in the UK (about 5,300 people a year).

There are around 100 different sub-types of sarcoma, which can be largely split into three groups:

- soft tissue sarcomas (e.g. leiomyosarcoma, liposarcoma)
- bone sarcomas (e.g. chondrosarcoma, osteosarcoma)
- gastro-intestinal stromal tumours (also known as GISTs).

Every day, Sarcoma UK hears about the issues faced by patients and their families. However, data collection by the NHS is incredibly poor for sarcoma. In turn, this makes it difficult to persuade the NHS and Government to make the changes that are desperately needed and long overdue if the care given to sarcoma patients is to improve. Accurate and high-quality data is essential to monitor and improve outcomes for patients, and drive research progress.

To try and address this, in 2015, Sarcoma UK worked with Quality Health to create one of the most comprehensive surveys undertaken into the experiences of people diagnosed with sarcoma in the UK. Data about patient experience, from their first concerns that something was wrong, through their diagnosis, treatment, and follow-up, were collected. It revealed that sarcoma patients encounter some of the poorest experiences of any cancer, significantly lower than those diagnosed with the most common cancers.

Following the success of this survey and the invaluable data it collected, Sarcoma UK decided to re-run the survey in 2020 with a broadened purpose: to collect data on sarcoma patient experience in order to build an evidence-base for influencing. This was also expanded beyond adult sarcoma patients to include children with sarcoma and family and carers of those with sarcoma.

Sarcoma UK shared the survey through its supporter network and on social media. There were 1,117 responses to the survey:

- 661 patients over 16
- 56 parents of patients under 16
- 400 family and carers of sarcoma patients

Adult patient demographics:

- 71% of respondents had soft tissue sarcoma, 16% had a bone sarcoma, and 14% had a GIST.
- 71% were female, 29% were male.
- Over a third of the respondents (38%) were aged between 41 and 55; 28% were aged between 56 and 70; and 3% were aged 16 to 24; 20% were aged 25 to 40; 9% were aged 71-80, and 1% were older than 80.
- A vast majority (85%) were treated in England, 10% in Scotland, and 2% for each of Wales and Northern Ireland.

Once again, the results from the survey have created a robust dataset. The data has allowed us to build a clearer picture of patients' experience of the diagnosis, treatment and emotional impact of sarcoma. It has both drawn attention to and given evidence for areas where further policy and campaigning work can be undertaken.

## 1.2. Awareness of sarcoma and early diagnosis

This survey found sarcoma patients were no more likely to know about sarcoma than the general public, with 79% not having heard about sarcoma before their diagnosis. This is in line with a YouGov poll commissioned by Sarcoma UK in 2019, in which 75% of the public said they did not know what sarcoma was. Even among people who had heard of sarcoma, 30% didn't know what the symptoms are.

The difficulty faced is that while there are numerous signs and symptoms associated with sarcomas, they are often vague (such as a lump), can be attributed to other health problems, and sometimes signs are only noticed once the tumour is causing issues internally (such as for GISTs and other retro-peritoneal sarcomas). A quarter (25%) of 16-24 year olds waited more than a year after their symptoms began before going to see a primary care professional.

Further to this, primary care professionals are not used to seeing sarcomas; during a working lifetime a general practitioner (GP) may see many hundreds of benign tumours, but can only expect to see one or two patients with bone or soft tissue sarcomas. Consequently, GPs do not recognise the symptoms described to be a sarcoma, and either send the patient away, or put them on the wrong treatment. 22% of respondents were told at their first appointment with a primary care professional that their symptom(s) wasn't serious. One in 6 (17%) were given treatment for another condition after this appointment.

It is widely acknowledged that an early and accurate diagnosis can have a significant impact on the outcome for cancer patients, and this is certainly true for sarcoma. However, delays in diagnosis, or indeed incorrect diagnosis, are not uncommon. 35% of respondents (including half of all bone sarcoma patients) saw a healthcare professional more than 3 times before they were referred for further tests. Furthermore, analysis of free text comments around diagnosis showed that the time before being referred was the most talked-about theme for the 16+ group.

Issues with diagnosis are commonplace in sarcoma and can be devastating for patients. Around a third of respondents (30%) took more than 6 months to receive an accurate diagnosis, with 17% waiting more than a year. In order that sarcoma diagnostic tests are seen by specialist pathologists, and that patients are cared for by experts in the cancer field, the NHS England Service Specification for Sarcoma makes clear that all patients suspected of having sarcoma should be referred into a sarcoma specialist centre. Shockingly, 13% of adult respondents were not treated by a specialist sarcoma team.

## 1.3. Impact of sarcoma

Although sarcomas are a heterogeneous group of bone and soft tissue cancers, one clear linking factor is the emotional impact they have. Indeed, psychosocial wellbeing is poorer than the general population, regardless of whether patients have amputation, limb-sparing surgery, or rotationplasty.

90% of respondents said that the diagnosis and treatment of sarcoma negatively affected their overall mental health/emotional wellbeing (20% answered “slightly”; 45% to “some extent” and 25% “severely”). Despite this, 40% said they were not given enough emotional support by hospital staff (formal support, such as counselling).

Anxiety was shown to be one of the most common late effects impacting day-to-day life by over half of patients, with the number one largest worry being whether the cancer would come back.

Carers and family also said that caring for someone with sarcoma had a huge impact on their lives – almost a quarter (24%) said they spent more than 50 hours a week providing care and support. 81% of respondents said that sarcoma treatment of their family or friend had a temporary or permanent impact on their ability to work or complete education, with 18% having to permanently stop work or education.

Mental health worries were clear for families and carers of sarcoma patients. Almost all (94%) said that they felt either depressed or anxious more often since the diagnosis or constantly felt depressed or anxious. When family and carers were asked what the biggest improvements to sarcoma services would be, support was the most popular choice.

## 1.4. Information and support

For cancer patients, getting the right information at the right time can make a big difference. It can help people make decisions about treatment, prepare better for treatment, and also cope with the adverse effects better. This includes reducing depression, increasing satisfaction with treatment, improving communication with family and even improving quality of life. However, in our survey, 45% of respondents said they were not given enough information at diagnosis.

Patient education and meeting patients’ information needs is a fundamental aspect of patient-centred care – it is only when patients are fully informed that they can become an active partner in the process of their care. Despite this, over half (54%) were not given a written care plan telling them all the information they needed about their sarcoma treatment from start to finish. However, the NHS England Five Year Forward View and the Cancer Taskforce Strategy outlines a commitment to ensuring that ‘every person with cancer has access to the elements of the Recovery Package [including this care plan] by 2020’.

Despite local support groups existing, most patients were not aware of them. Over half (52%) were not told by their medical teams about local cancer groups/charities, and of the remaining half, only 54% were told about a sarcoma-specific group.

# 2. Background and methodology

## 2.1. Background

In 2015, Sarcoma UK ran its first National Sarcoma Survey. This looked to provide information on the state of sarcoma patient experience in the UK. Much has changed across the UK's health services in the last 5 years, and as such it is logical that the experience of patients is unlikely to have remained the same.

Last year, Sarcoma UK created a new policy and public affairs function within the charity, which looks to influence health policy in order to improve the sarcoma landscape in the UK. This includes areas such as early diagnosis, referral into sarcoma specialist centres, and access to the best treatments. Such influencing requires the creation of robust data to demonstrate that issues exist and to provide potential solutions. Therefore, this survey was designed and run to collect such data.

## 2.2. Questionnaire design and development

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, which goes deeper than last time in an attempt to get richer data.

As a part of the process, cognitive testing was carried out with nine volunteers with a range of types of sarcoma, who were willing to fill in the questionnaire and discuss various aspects of its design. This included comments on whether the answer options accurately represented their experiences, if there was anything missing, and the length of the survey. After these interviews, the feedback was provided to Sarcoma UK, who agreed amendments. In addition, the draft questionnaires were reviewed by a Sarcoma Clinical Nurse Specialist who provided further comments, with a particular focus on the suitability of the questions about under 16s. These exercises contributed to the refinement of the questionnaires into finished versions.

## 2.3. Sample

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.

## 2.4. Timescales and fieldwork

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.

# 3. Responses

## 3.1. Response rate

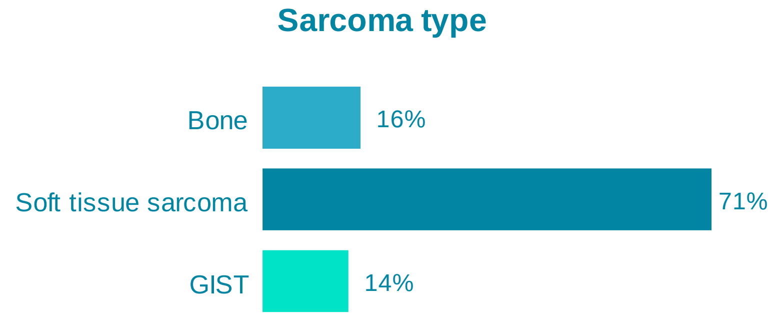
The number of responses for each of the questionnaires was as follows:

| | |
|---|---|
| Adult | 661 |
| Parents of Under 16s | 56 |
| Family and Carers | 400 |
| **Total** | **1,117** |

## 3.2. Respondent characteristics

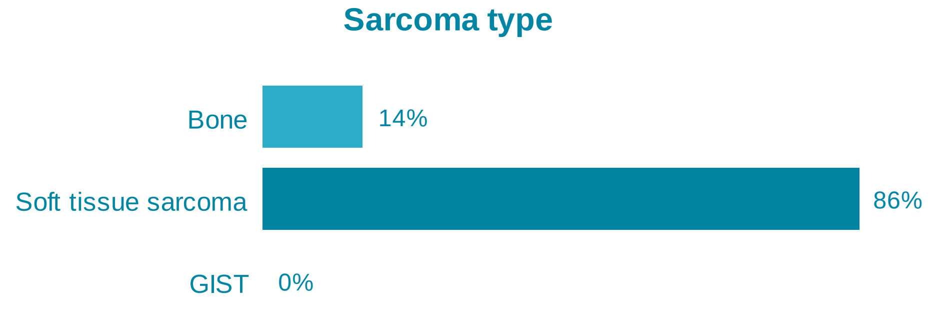
### Sarcoma type

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.)



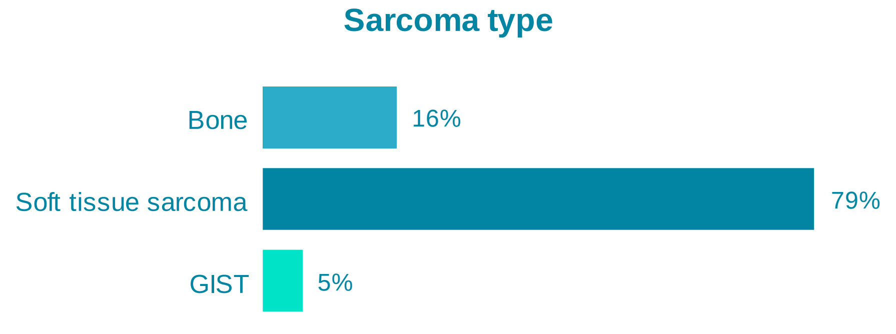
*From question 46a, 16+ questionnaire: What type of sarcoma do you have?*

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.



*From question 46a, Parent questionnaire: What type of sarcoma do they have?*

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.)

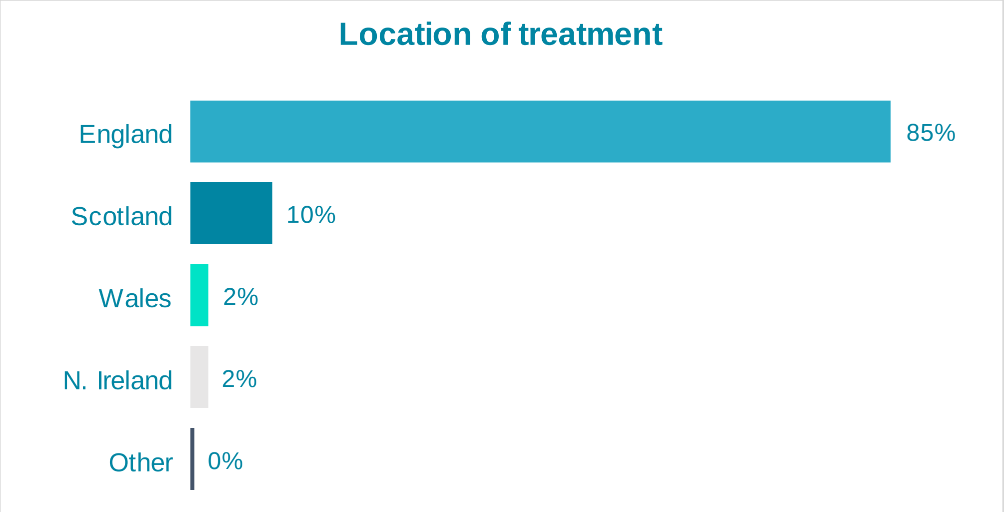


*From question 24a, Family & Carers questionnaire: What type of sarcoma do they have?*

The full set of subtypes is included with this report as Appendix B5 and the list of sarcoma locations are included as Appendix B4.

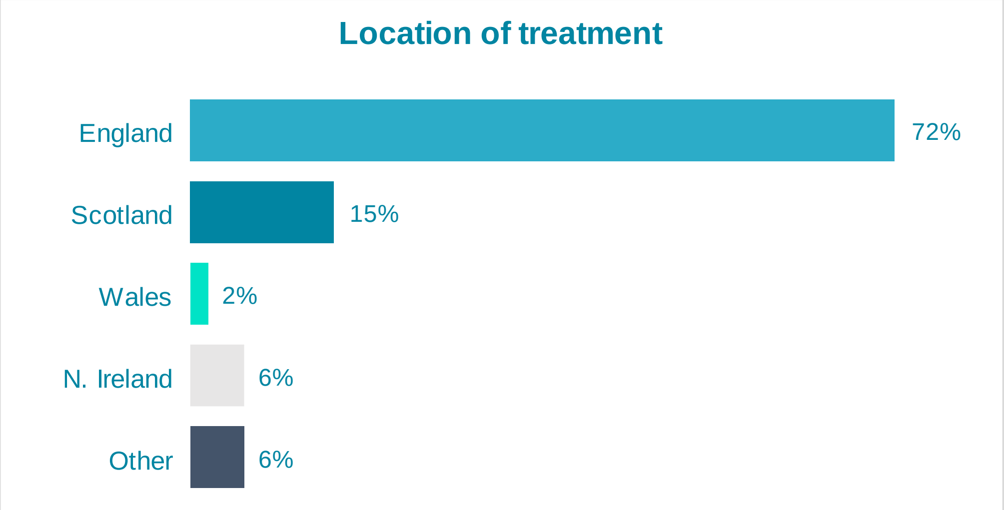
## Location

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.)



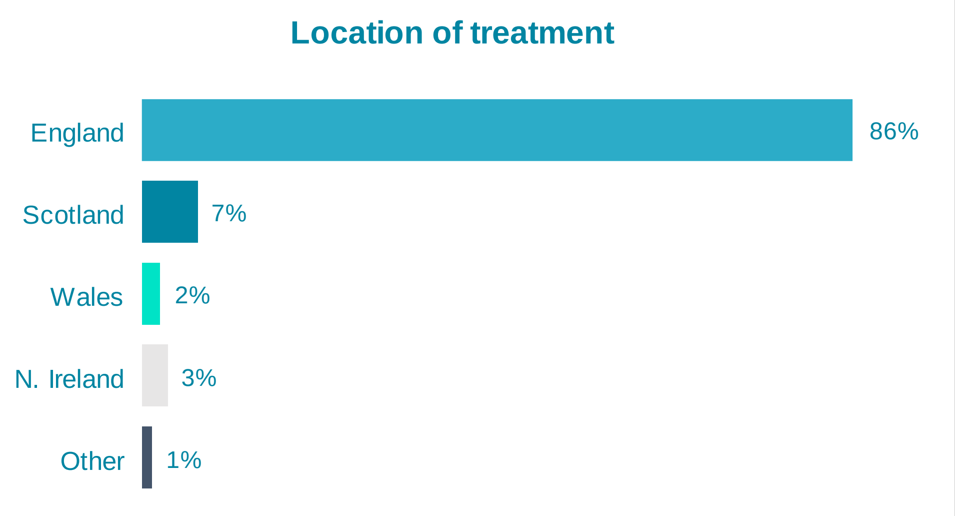
*From question 48, 16+ questionnaire: Where were you treated?*

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.)



*From question 48, Parent questionnaire: Where were they treated?*

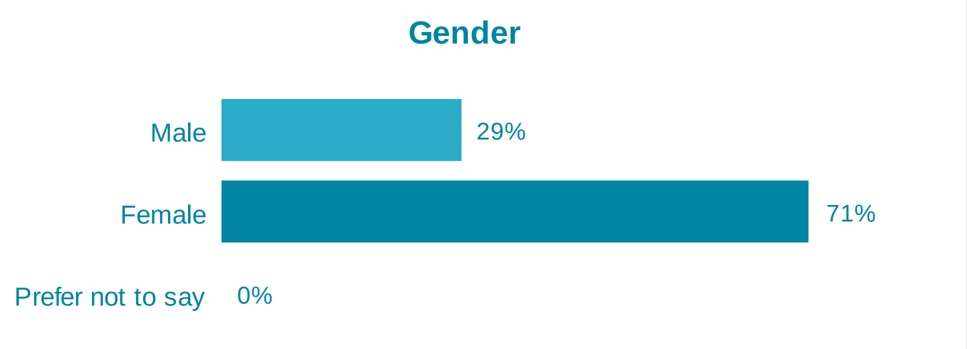
For the family and carers questionnaire, 86% of respondents said their family member or friend was treated in England, 7% said their family member or friend was treated in Scotland, 3% said their family member or friend was treated in Northern Ireland, 2% said their family member or friend was treated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



*From question 26, Family & Carers questionnaire: Where were they treated?*

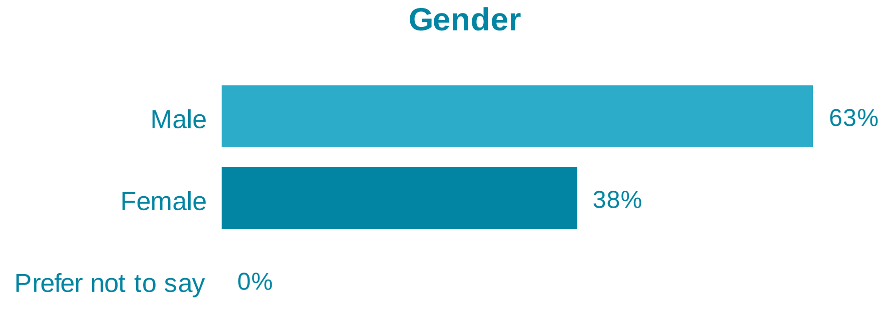
## Gender

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



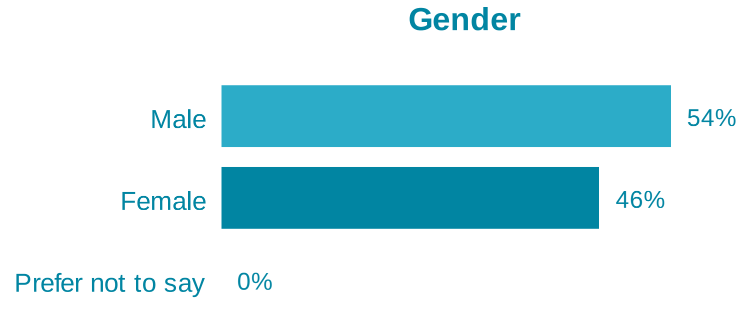
*From question 49, 16+ questionnaire: Are you male or female?*

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



*From question 49, Parent questionnaire: Are they male or female?*

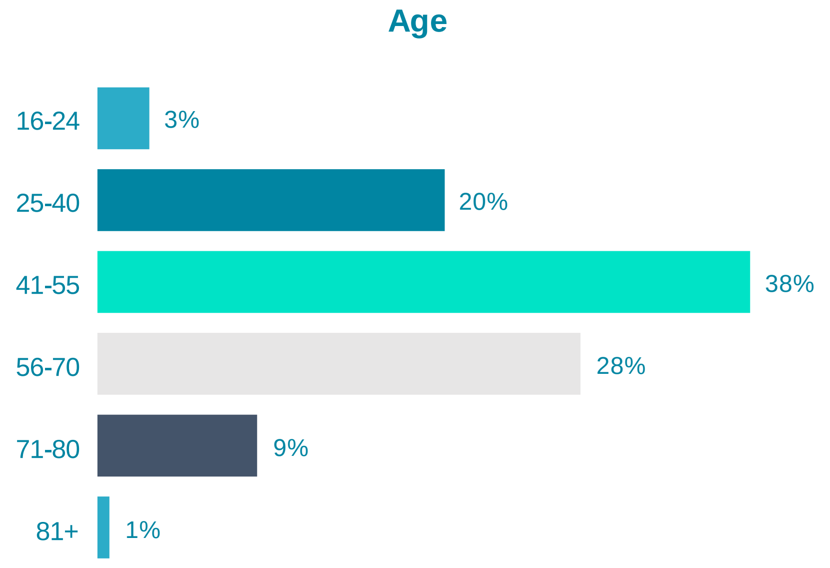
For the family and carers questionnaire, 54% of respondents said their family member or friend is male, and 46% said their family member or friend is female. (6 people did not answer this question).



*From question 27, Family & Carers questionnaire: Are they male or female?*

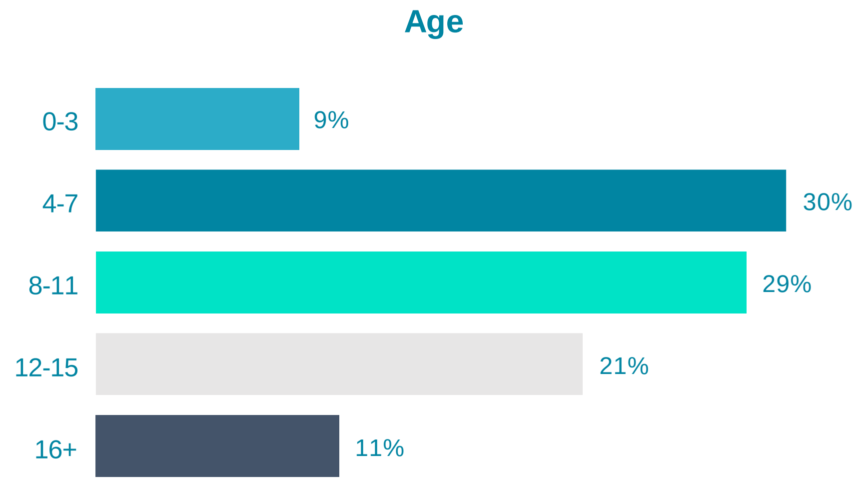
## Age

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.)



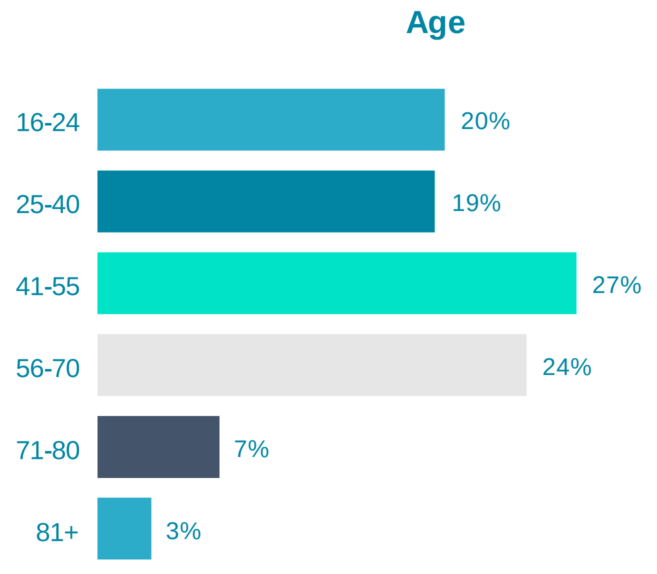
*From question 50, 16+ questionnaire: How old are you?*

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+.



*From question 50, Parent questionnaire: How old are they? (If you are bereaved, please answer with the patient's age at diagnosis)*

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.)



*From question 28, Family & Carers questionnaire: How old are they? (If you are bereaved, please answer with the patient's age at diagnosis)*

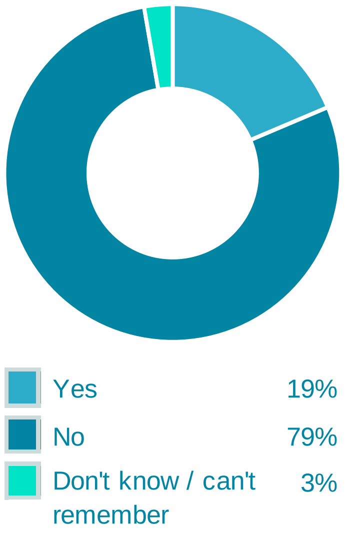
# 4. Results – 16+ Questionnaire

## 4.1. Diagnosis

### Sarcoma awareness

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

**Heard about sarcoma before diagnosis**

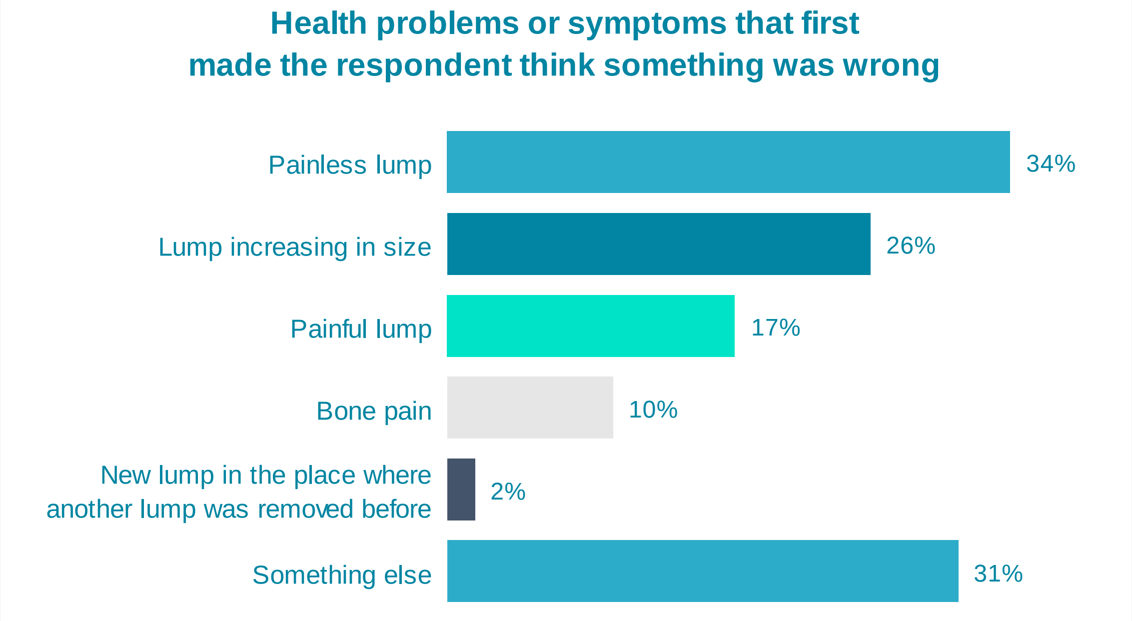


*From question 1, 16+ questionnaire: Had you heard about sarcoma before your diagnosis?*

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)*



*From question 2, 16+ questionnaire: What were the main health problems or symptoms that first made you think something was wrong?*

**31%** of respondents chose 'something else'. The counts of 'something else' responses are included with this report as Appendix B1.

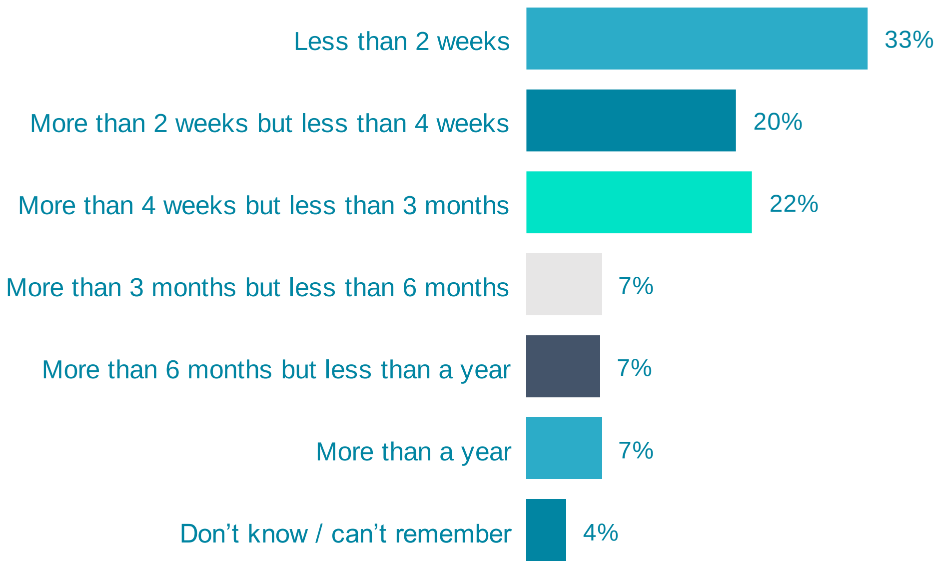
In addition, when the family and carers were asked if their family member / friend had mentioned they had problems or symptoms, the most common choices, again, were a lump increasing in size (**30%**) and a painless lump (**27%**). *(Q3 Family & Carers Questionnaire)*

**28%** chose 'something else'. The counts of 'something else' responses are included with this report as Appendix B1.

## 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

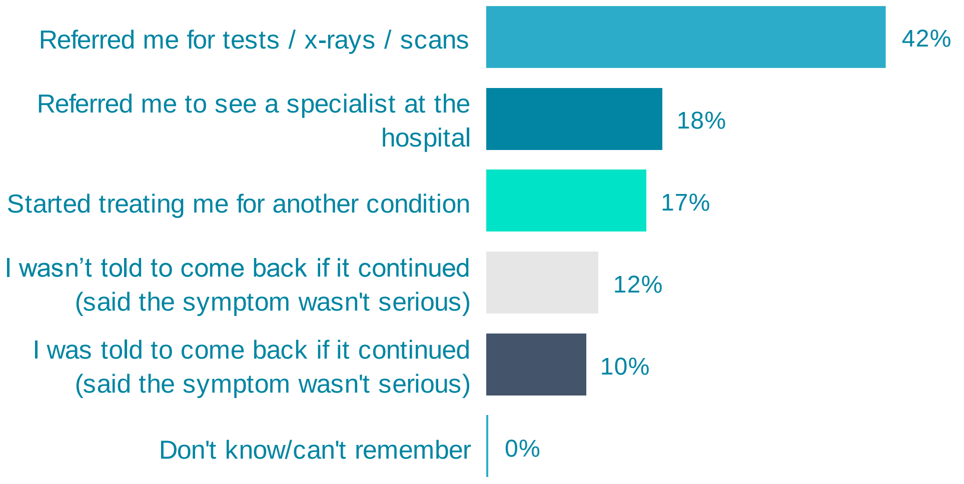


*From question 3, 16+ questionnaire: How long was it from the time you first thought something might be wrong with you until you first saw a GP, Nurse or went to A&E?*

## 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

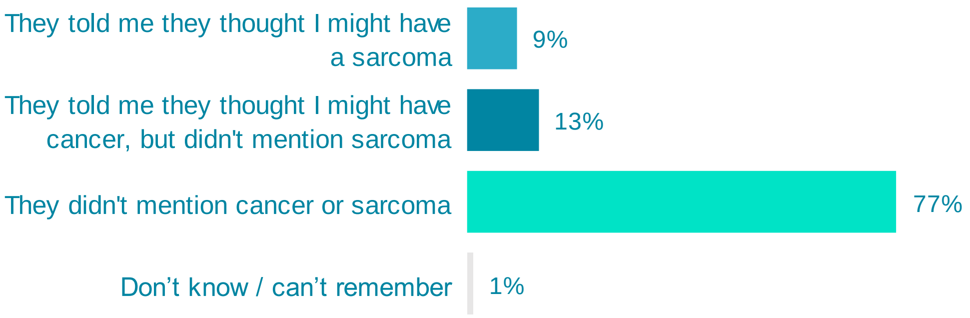


*From question 5, 16+ questionnaire: What did this healthcare professional say / do?*

## 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**

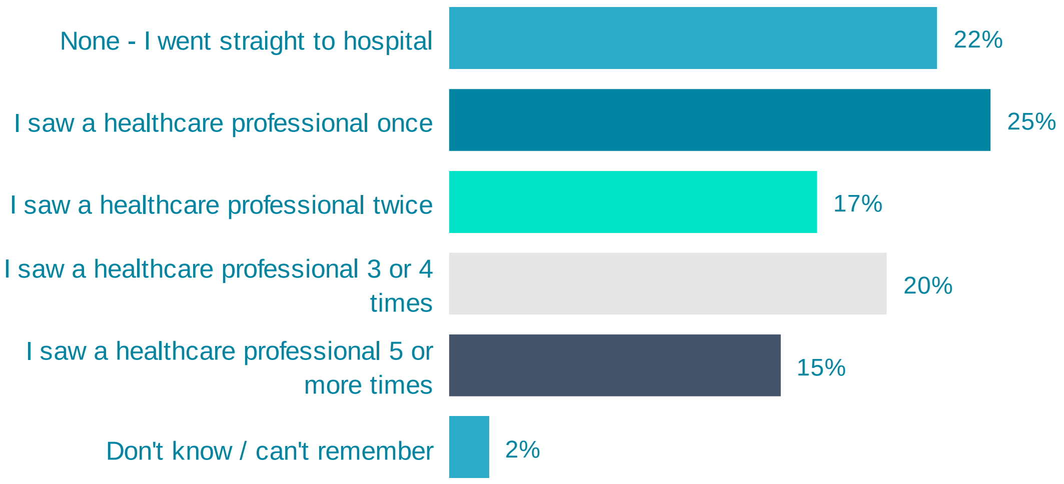


*From question 6, 16+ questionnaire: Did the healthcare professional tell you that they thought you might have a sarcoma?*

## 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.’*

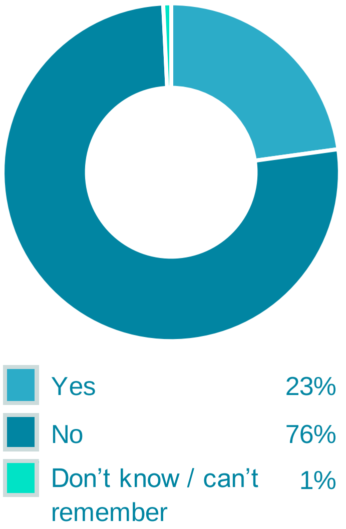
> *‘Not disease but GP attempted to aspirate my "ganglion" to then find out it was a solid mass.’*

> *‘Told to take paracetamol for a sprained foot.’*

> *‘Lump was diagnosed as cyst benign.’*

> *‘Iron tablets for anaemia.’*

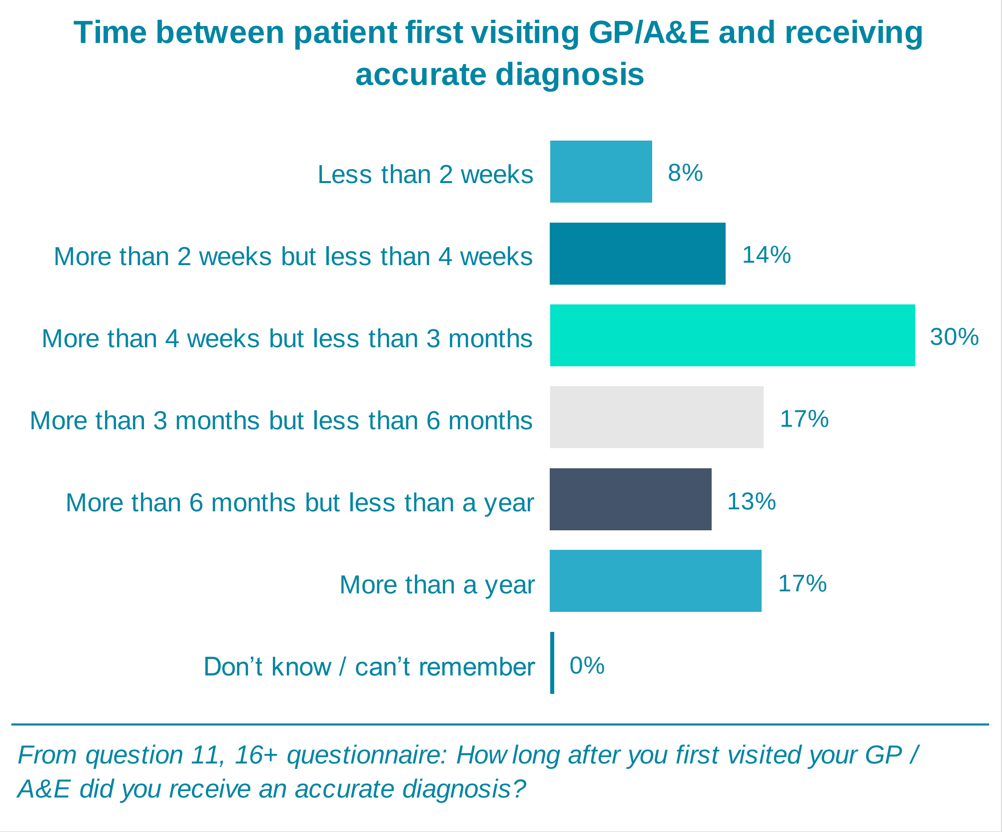
**Patient started treatment for another disease**



*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)*



*From question 11, 16+ questionnaire: How long after you first visited your GP / A&E did you receive an accurate diagnosis?*

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.’*

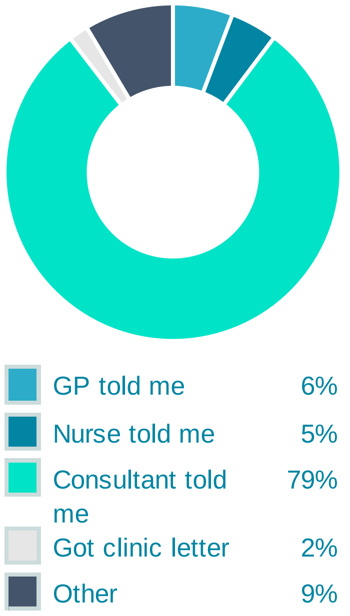
> *‘Read it in patient portal. I was originally told it was benign.’*

> *‘Phone call from consultant secretary!’*

> *‘After an MRI.’*

> *‘Surgeon who removed the tumour told me.’*

**Source of first communication about sarcoma diagnosis**

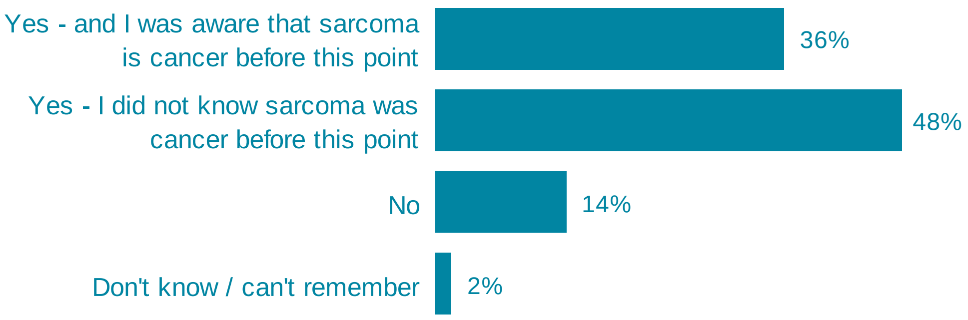


*From question 12, 16+ questionnaire: How did you learn about your sarcoma diagnosis?*

## 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)*

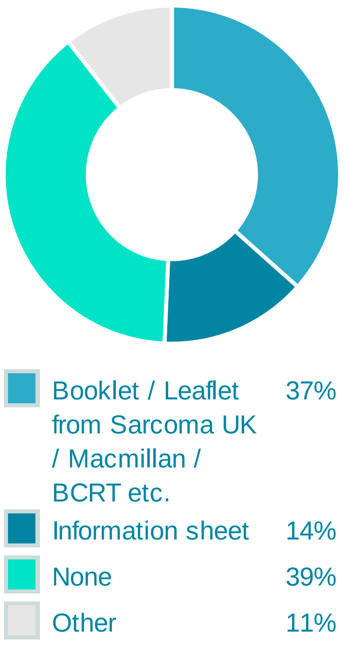
**11%** chose ‘other’. This included comments such as:

> *‘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.’*

> *‘Detailed explanation from an experienced and leading sarcoma surgeon.’*

> *‘Printed Google search.’*

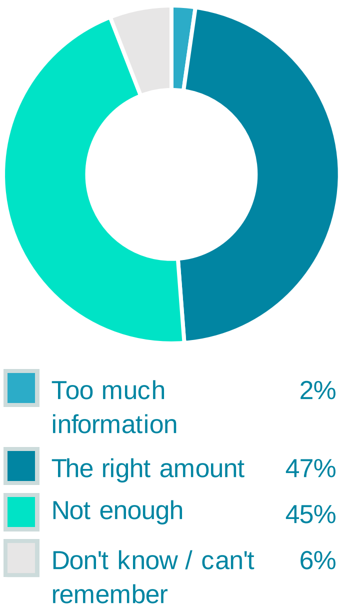
**Information given at diagnosis**



*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**

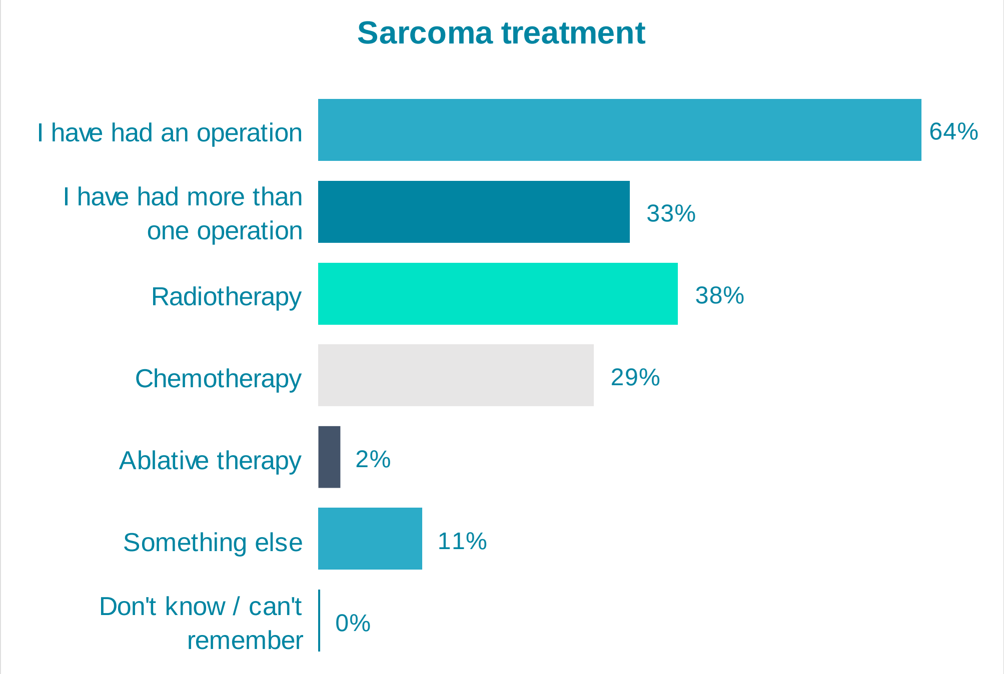


*From question 14b, 16+ questionnaire: At diagnosis, how much information were you given?*

## 4.2. Treatment

### Type of treatment

Nearly two thirds of respondents (**64%**) have had one operation, a third have had more than one operation, **38%** have had radiotherapy, **29%** have had chemotherapy and **2%** have had ablative therapy. *(Q15, 16+ Questionnaire)*



*From question 15, 16+ questionnaire: What treatment have you had for your sarcoma?*

**11%** of respondents chose ‘something else’. This included comments such as:

> *‘Immunotherapy.’*

> *‘Hormone therapy.’*

> *‘Proton beam therapy.’*

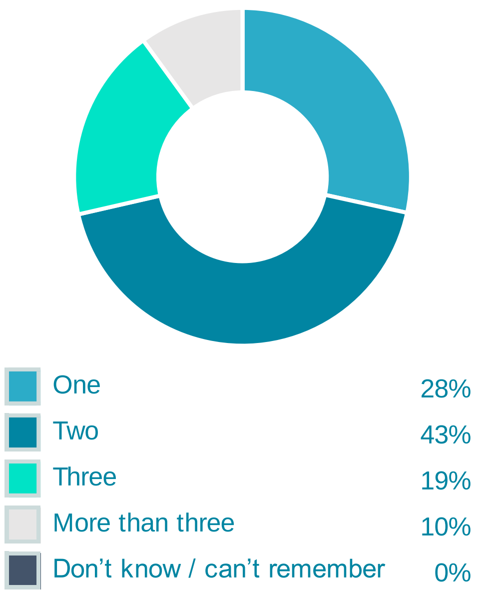
> *‘Imatinib.’*

> *‘On clinical trial.’*

## Number of hospitals attended for treatment

When asked how many hospitals they had attended for treatment, nearly half of respondents (**43%**) said two. **28%** had attended one hospital, **19%** had attended three, and **10%** had attended more than three.
*(Q16, 16+ Questionnaire)*

**Number of hospitals attended for sarcoma treatment**

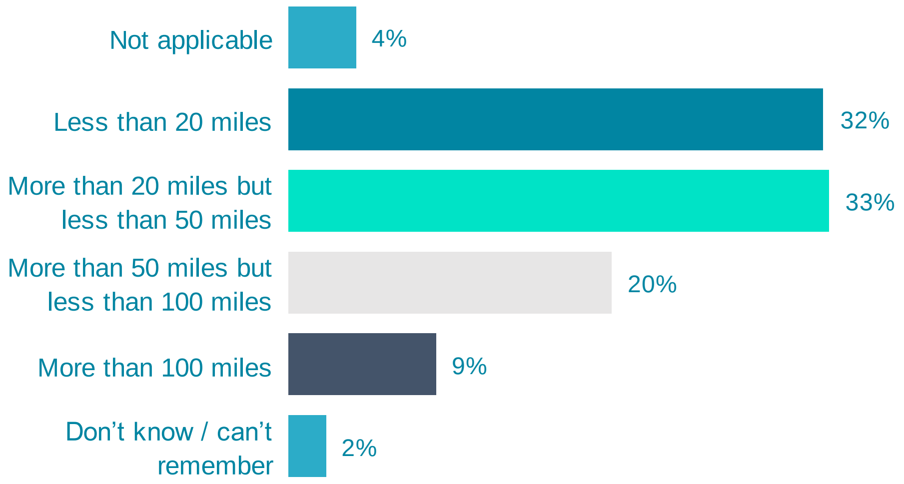


*From question 16, 16+ questionnaire: How many hospitals have you attended for treatment for your sarcoma?*

## Distance from specialist sarcoma centre

When asked how far they lived from their specialist sarcoma centre, the most common choices were less than 20 miles (**32%**) and between 20 and 50 miles (**33%**). A further **20%** said they lived between 50 and 100 miles away, and **9%** said they lived more than 100 miles away.
*(Q17, 16+ Questionnaire)*

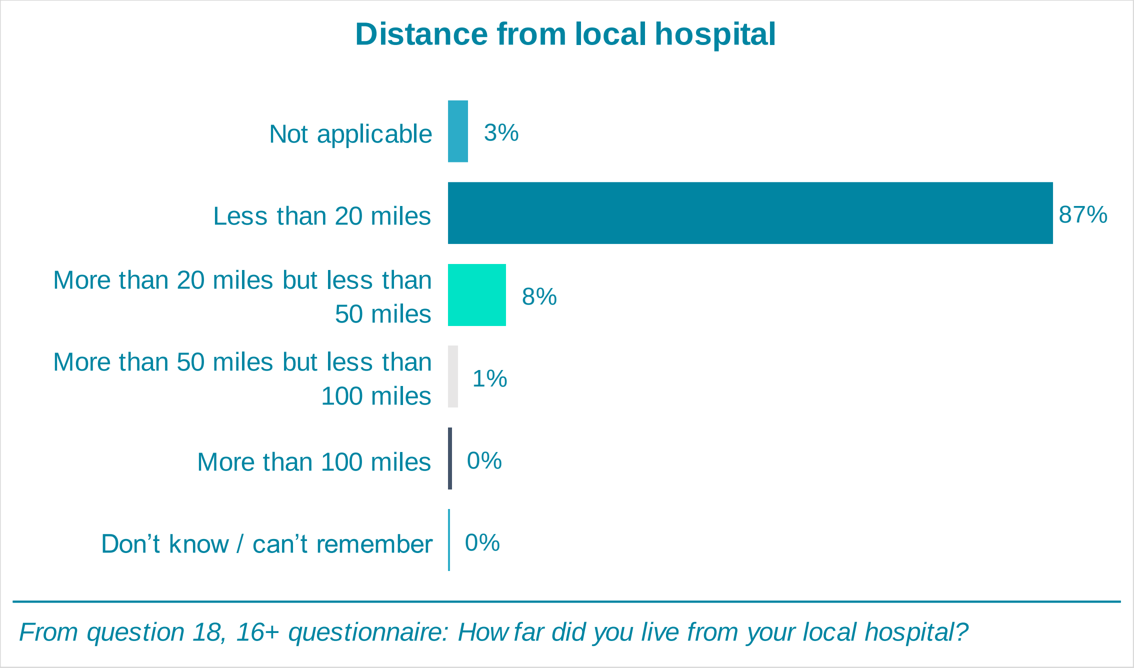
**Distance from specialist sarcoma centre**



*From question 17, 16+ questionnaire: How far did you live from your specialist sarcoma centre?*

## Distance from local hospital

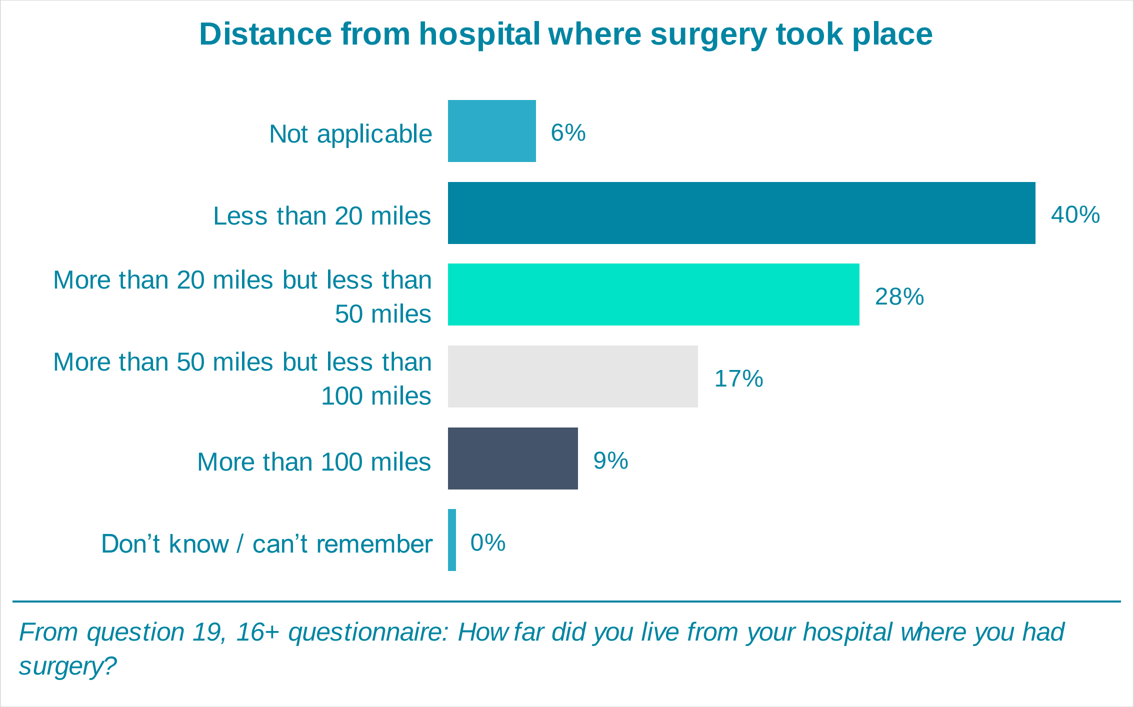
The majority of respondents (**87%**) live less than 20 miles from their local hospital. **8%** live between 20 and 50 miles, and **1%** live between 50 and 100 miles. *(Q18, 16+ Questionnaire)*



*From question 18, 16+ questionnaire: How far did you live from your local hospital?*

## Distance from where they had surgery

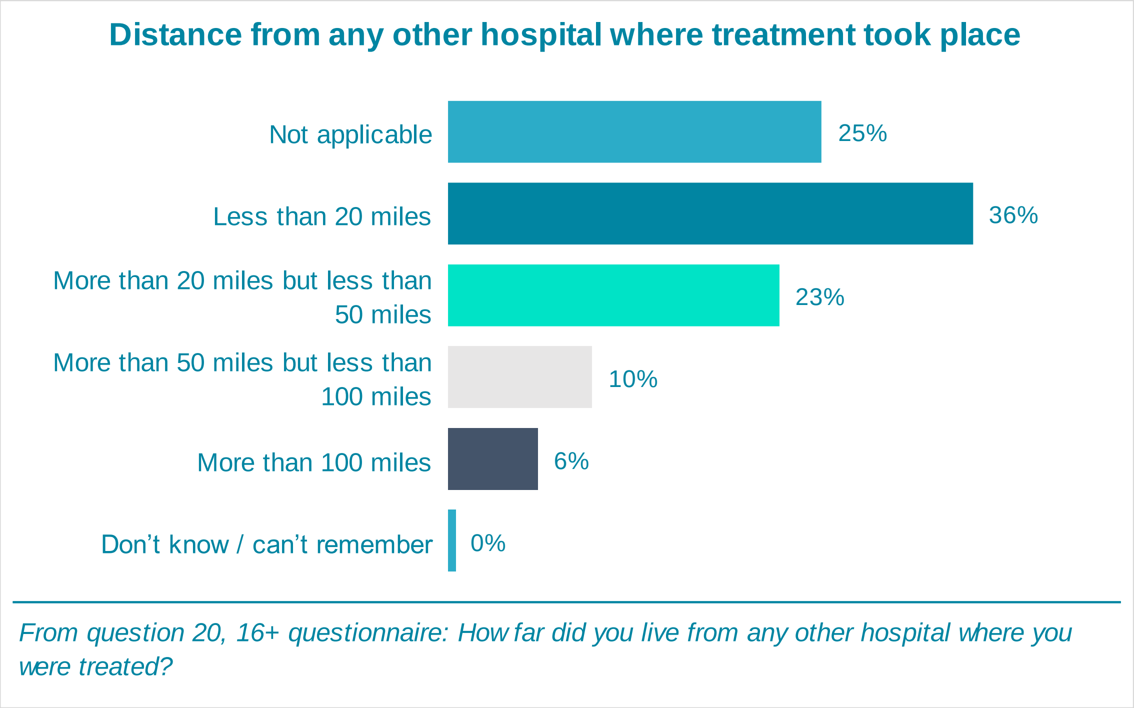
When asked how far they lived from the hospital where they had surgery, **40%** of respondents chose less than 20 miles. **28%** said they lived between 20 and 50 miles away, **17%** said they lived between 50 and 100 miles away, and **9%** said they lived more than 100 miles away. *(Q19, 16+ Questionnaire)*



*From question 19, 16+ questionnaire: How far did you live from your hospital where you had surgery?*

## Distance from treatment

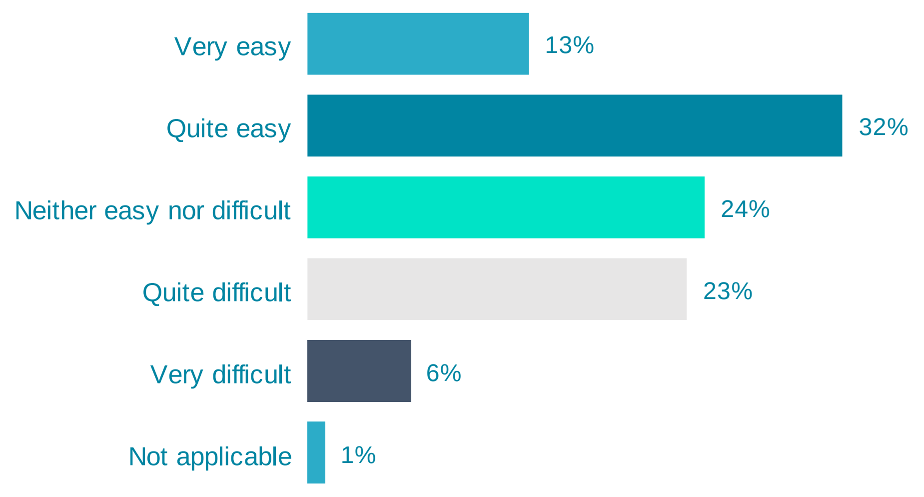
**36%** of respondents said they live less than 20 miles from any other hospital where they were treated. **23%** said they lived between 20 and 50 miles away, **10%** said they lived between 50 and 100 miles away, and **6%** said they lived more than 100 miles away. *(Q20, 16+ Questionnaire)*



## Ease of travelling to treatment

When asked how easy or difficult it has been to travel for treatment, the most common choice was quite easy (**32%**). **24%** said it was neither easy nor difficult, while a further **23%** said it was quite difficult. **13%** said it was very easy and **6%** said it was very difficult. *(Q21, 16+ Questionnaire)*

How easy or difficult it was to travel to treatment

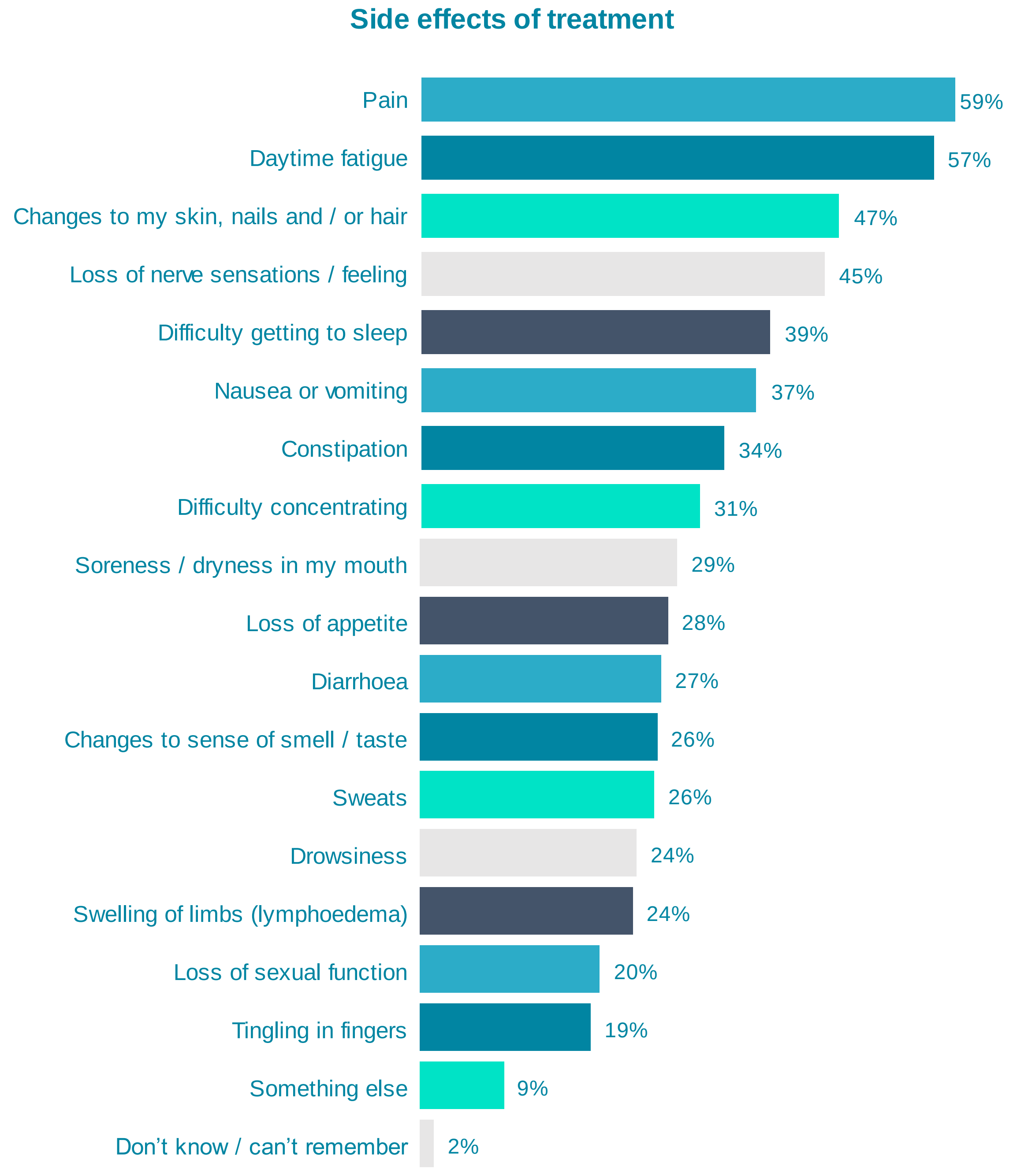


*From question 21, 16+ questionnaire: How easy or difficult has it been to travel for your treatment?*

When the family and carers were asked how easy it was to travel for their family member / friend's treatment, they answered more negatively. The most common choice was quite difficult (36%). *(Q8 Family & Carers Questionnaire)*.

## Side effects of treatment

The most commonly reported side effects of treatment were pain (**59%**); daytime fatigue (**57%**); changes to skin, nails and/or hair (**47%**); and loss of nerve sensations/feeling (**45%**). The chart below shows all the symptoms listed. *(Q22, 16+ Questionnaire)*



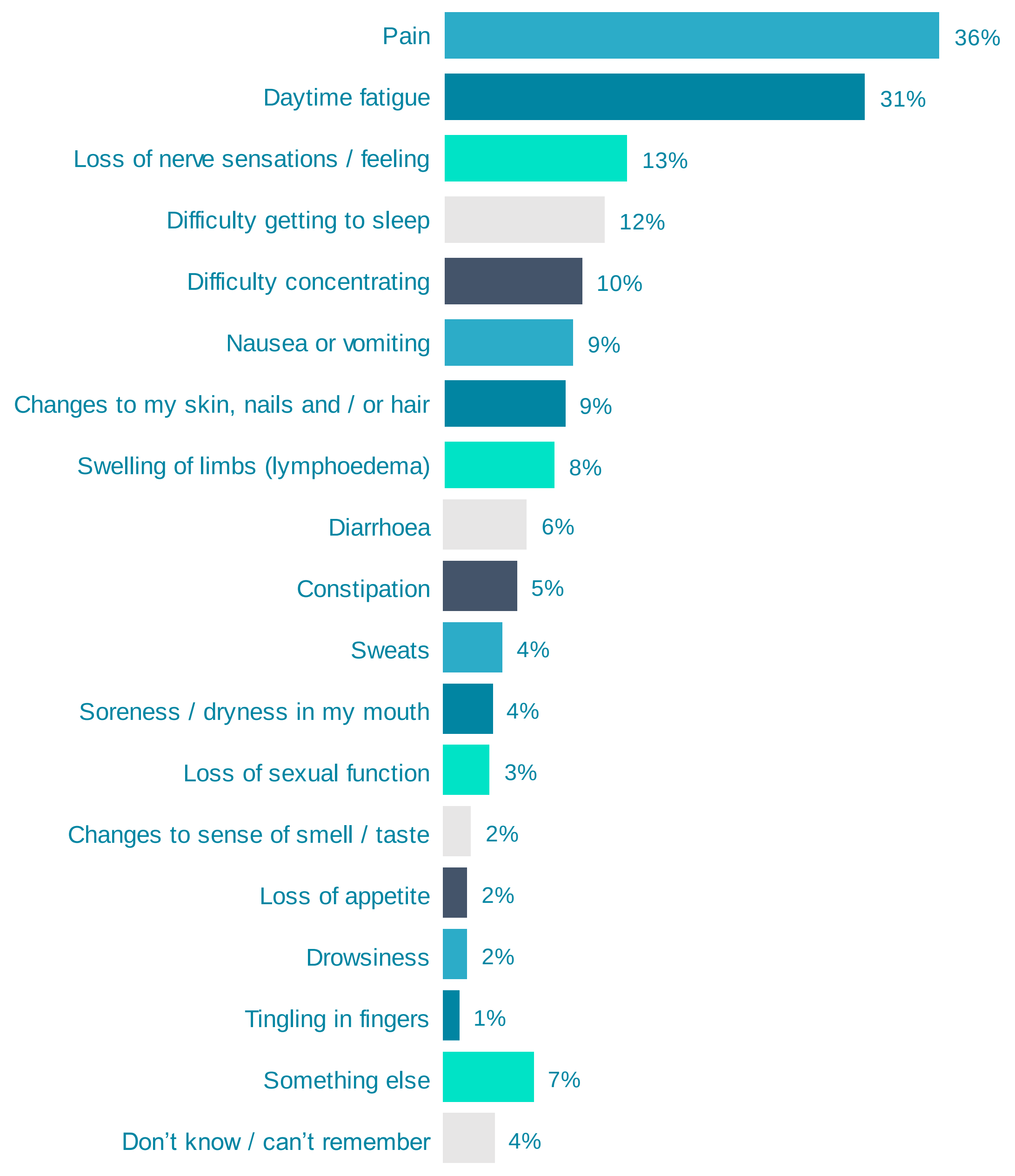
*From question 22, 16+ questionnaire: Have you had any of the following side effects from your treatment?*

**9%** chose 'something else.' The counts of 'something else' responses are included with this report as Appendix B2.

## Side effects with the greatest impact

When asked which side effects have had the greatest impact on their life, the most common answers were pain (**36%**) and daytime fatigue (**31%**). All other answer options had far fewer respondents, with the next most common choice being loss of nerve sensations/feeling, at **13%**. *(Q23, 16+ Questionnaire)*

### Side effects that had the greatest impact



*From question 23, 16+ questionnaire: If you have had any of these side effects, which has had the greatest impact on your life?*

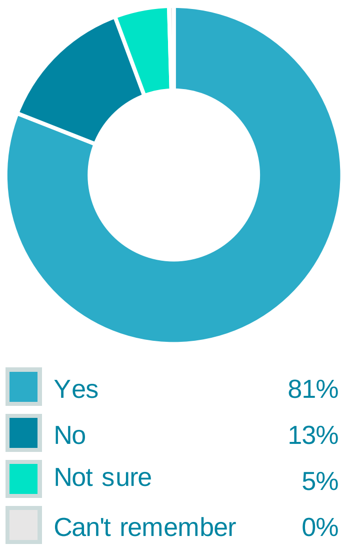
**7%** chose ‘something else’. The counts of ‘something else’ responses are included with this report as Appendix B3.

In addition, when the family and carers were asked which side effects had the greatest impact on their family member / friend’s life, the most common choices were, again, pain (**65%**) and daytime fatigue (**49%**). *(Q10 Family & Carers Questionnaire)*

**14%** chose ‘something else’. The counts of ‘something else’ responses are included with this report as Appendix B3.

## Sarcoma specialist team

**Treated by a specialist sarcoma cancer team**



*From question 24, 16+ questionnaire: Were you treated by a specialist sarcoma cancer team?*

**81%** of respondents were treated by a sarcoma specialist cancer team. **13%** were not and **5%** said they weren’t sure. *(Q24, 16+ Questionnaire)*

Respondents who chose ‘no’ were invited to specify who treated them. This included comments such as:

> *‘Gynaecologist.’*

> *‘Plastics consultant.’*

> *‘Breast surgeon.’*

> *‘Head and neck cancer specialist.’*

In addition, when the family and carers were asked if their family member / friend was treated by a sarcoma specialist cancer team **75%** said they were, **15%** said they were not, and **10%** said they were not sure. *(Q9 Family & Carers Questionnaire)*

Respondents who chose ‘no’ were invited to specify who treated their family member / friend. This included comments such as:

> *‘Teenage cancer team.’*

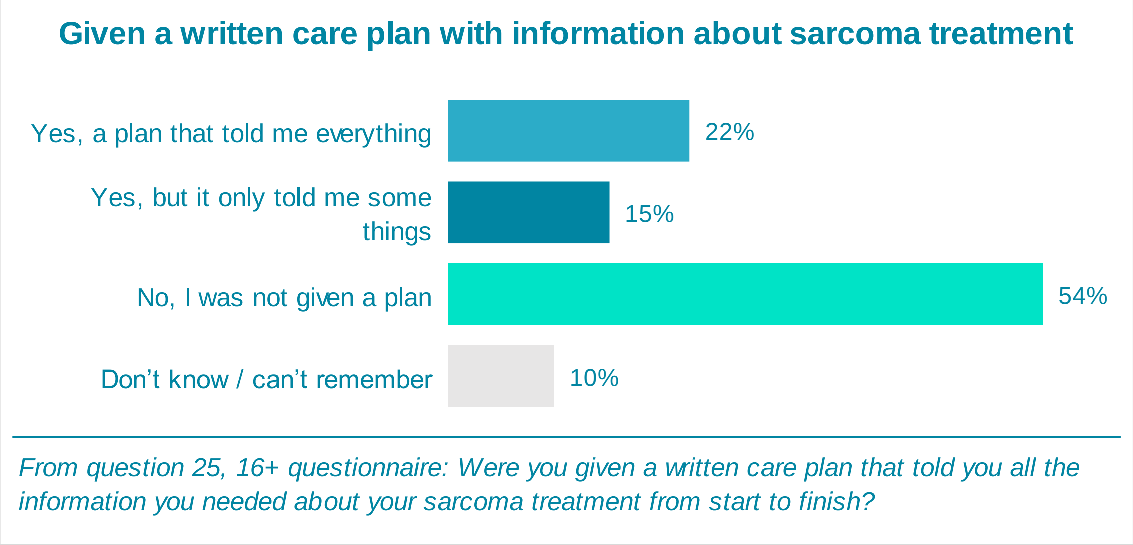
> *‘General hospital on cancer ward.’*

> *‘A specialist liver surgeon and then the cancer centre for radiotherapy and chemotherapy.’*

Analysis showed that a patient’s overall mental health and wellbeing was no more or less likely to be negatively affected depending on if they are treated by a sarcoma specialist team (S1). Respondents were equally affected whichever setting they were treated in. Please see 5.4 for all additional cross tabulation analysis.

## Care plan

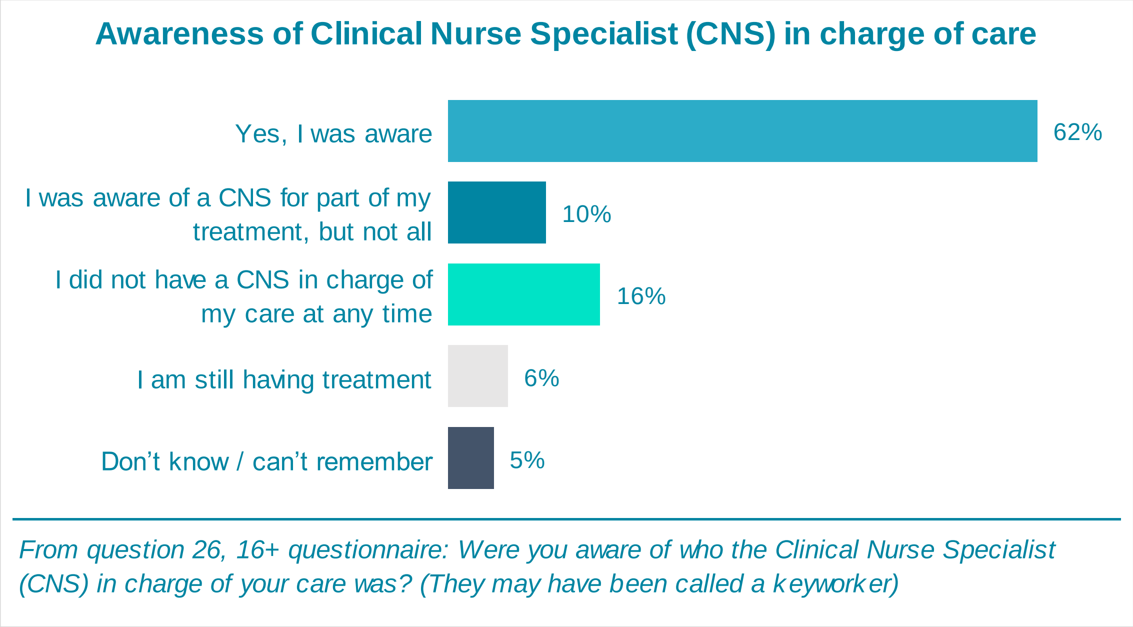
Over half of respondents (**54%**) said they were not given a care plan. **22%** said they were and it told them everything, while **15%** said they were but it only told them some things. *(Q25, 16+ Questionnaire)*



*From question 25, 16+ questionnaire: Were you given a written care plan that told you all the information you needed about your sarcoma treatment from start to finish?*

## Clinical nurse specialists

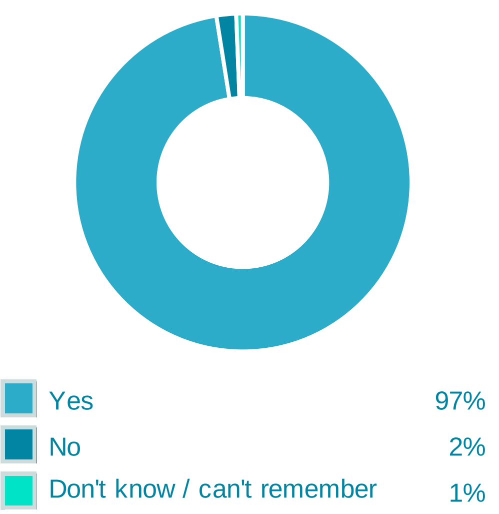
Nearly two-thirds of respondents (**62%**) said they were aware of who the CNS in charge of their care was. A further **10%** said they were aware of a CNS for part of their treatment but not all, and **16%** said they did not have a CNS in charge of their treatment at any time. *(Q26, 16+ Questionnaire)*



*From question 26, 16+ questionnaire: Were you aware of who the Clinical Nurse Specialist (CNS) in charge of your care was? (They may have been called a keyworker)*

Of those who said they have had a CNS, almost all knew how to contact them (**97%**). *(Q27, 16+ Questionnaire)*

**Knowledge of how to contact Clinical Nurse Specialist in charge**

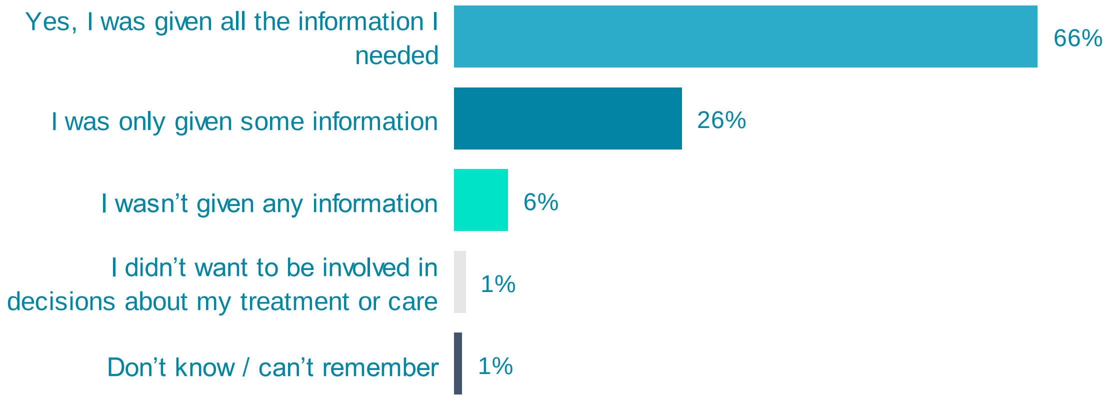


*From question 27, 16+ questionnaire: Did you know how to contact them?*

## Information to help make decisions

When asked if they were given enough information to help make decisions about their treatment and care, **66%** of respondents said they were given all the information they needed. **26%** said they were given some information and a further **6%** said they weren't given any information. *(Q28, 16+ Questionnaire)*

**Given enough information to help make decisions about treatment and care**



*From question 28, 16+ questionnaire: Were you given enough information to help you make decisions about your treatment and care?*

## Research

Half of respondents said they were not invited to take part in any research. **26%** said they were invited to consent for their samples to be used for research, **21%** were invited to a clinical trial, and **13%** were invited to complete a questionnaire. *(Q29, 16+ Questionnaire)*

*From question 29, 16+ questionnaire: Were you invited to take part in research? This may have been called a trial or a study*

**3%** chose 'yes, other'. This included comments such as:

> *'I was asked and consented, but it wasn't followed up.'*

> *'Was told trials may be applicable but determined by results of tests not yet received.'*

> *'Photos of the tumour before it was removed being used in research and teaching university students.'*

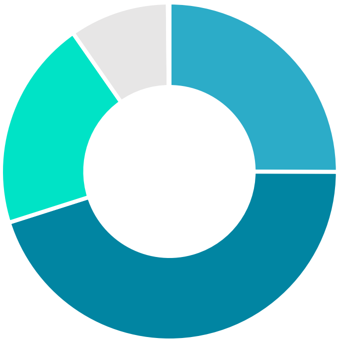
> *'100,000 Genomes Project.'*

## Impact on overall mental health / emotional wellbeing

**25%** of respondents said that their diagnosis and treatment of sarcoma has severely negatively affected their overall mental health / emotional wellbeing. **45%** said to some extent, **20%** said slightly and only **10%** said it had not at all.

*(Q31, 16+ Questionnaire)*

### Extent to which diagnosis and treatment of sarcoma negatively affected overall mental health / emotional wellbeing



| | | |
|---|---|---|
| 🟦 | Severely | 25% |
| 🟦 | To some extent | 45% |
| 🟩 | Slightly | 20% |
| ⬜ | Not at all | 10% |
| ⬛ | Don't know / can't remember | 0% |

*From question 31, 16+ questionnaire: To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing?*

## Emotional support from hospital staff

When asked if they were given enough emotional support from hospital staff throughout their treatment, **40%** of respondents said they would have liked more support. **18%** said they were definitely given enough emotional support and **26%** answered to some extent.

*(Q32, 16+ Questionnaire)*

### Given enough emotional support by hospital staff

| | | |
|---|---|---|
| 🟦 | Yes, definitely | 18% |
| 🟦 | Yes, to some | 26% |
| 🟩 | No, I would have liked more | 40% |
| ⬜ | I did not need emotional support | 16% |

*From question 32, 16+ questionnaire: Throughout your treatment, were you given enough emotional support from hospital staff? Emotional support here refers to formal support, such as counselling.*

## Referral to rehab services

The most common rehab service that respondents were referred to was physiotherapy (**36%**). **17%** were referred to emotional support, **12%** to occupational therapy, **11%** for nutrition / dietician and **6%** for mobility assistance. **41%** of respondents were not referred to any of the listed rehab services. *(Q33, 16+ Questionnaire)*

*From question 33, 16+ questionnaire: Were you referred to any of the following rehab services?*

**5%** chose ‘other’. This included comments such as:

> *‘Only where I pursued through my own private healthcare. Nothing NHS-wise was offered.’*

> *‘Acupuncture.’*

> *‘Hearing specialists. Chemo affected my hearing.’*

> *‘Lymphoedema clinic.’*

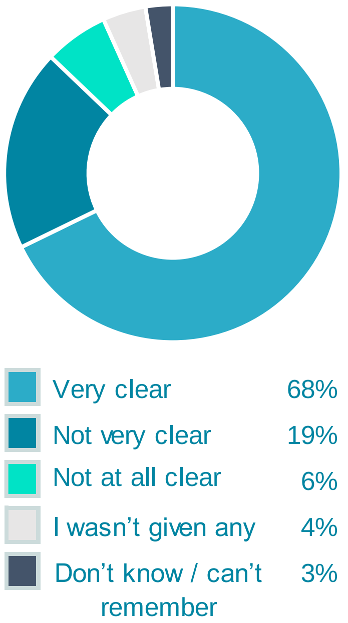
> *‘Local hospice complimentary therapy.’*

## 4.3. After treatment

### Treatment follow up

The majority of respondents (**68%**) said the information given to them by the hospital about how their treatment would be followed up was very clear. **19%** said it was not very clear and **6%** said it was not at all clear. (*Q34, 16+ Questionnaire*)

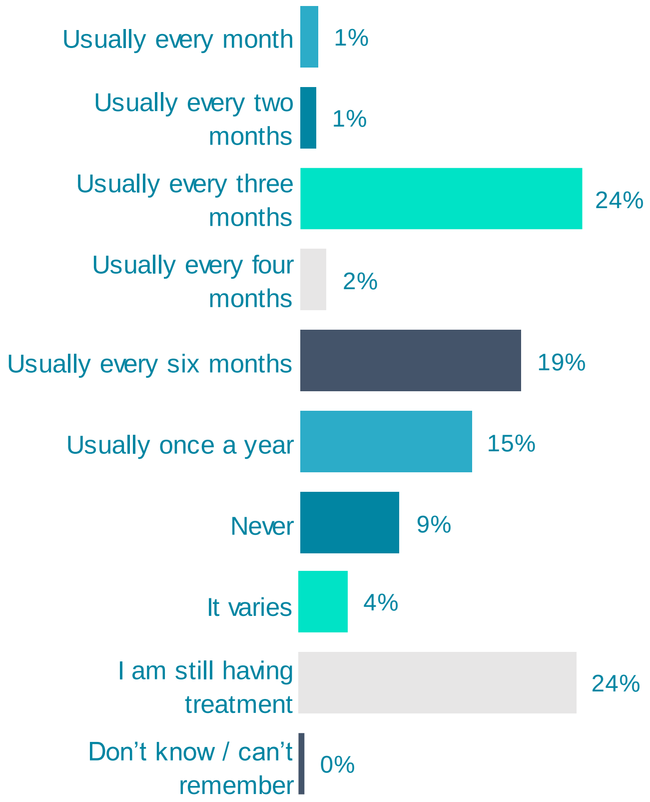
**Clarity of the information provided by the hospital about how treatment would be followed up**



*From question 34, 16+ questionnaire: How clear was the information given to you by the hospital about how your treatment would be followed up?*

When asked, after finishing treatment, how often they have follow-up appointments, **24%** said usually every three months. A further **19%** said usually every six months and **15%** said usually once a year. (*Q35, 16+ Questionnaire*)

**Frequency of sarcoma follow up appointments**

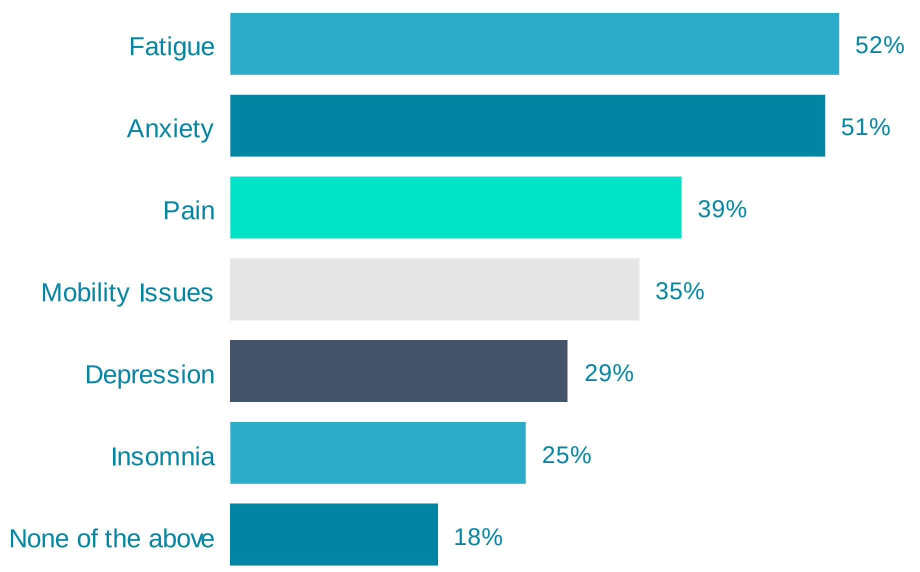


*From question 35, 16+ questionnaire: If you have finished treatment for your sarcoma, how often do you have follow up appointments at the hospital about your sarcoma?*

## Impact on day-to-day life

Around half of respondents said, after diagnosis and treatment, fatigue (**52%**) or anxiety (**51%**) impacts their day-to-day life. **39%** said pain impacts their life, **35%** said mobility issues, **29%** said depression and **25%** said insomnia. **18%** said their day-to-day life was not impacted by any of these factors. *(Q36, 16+ Questionnaire)*

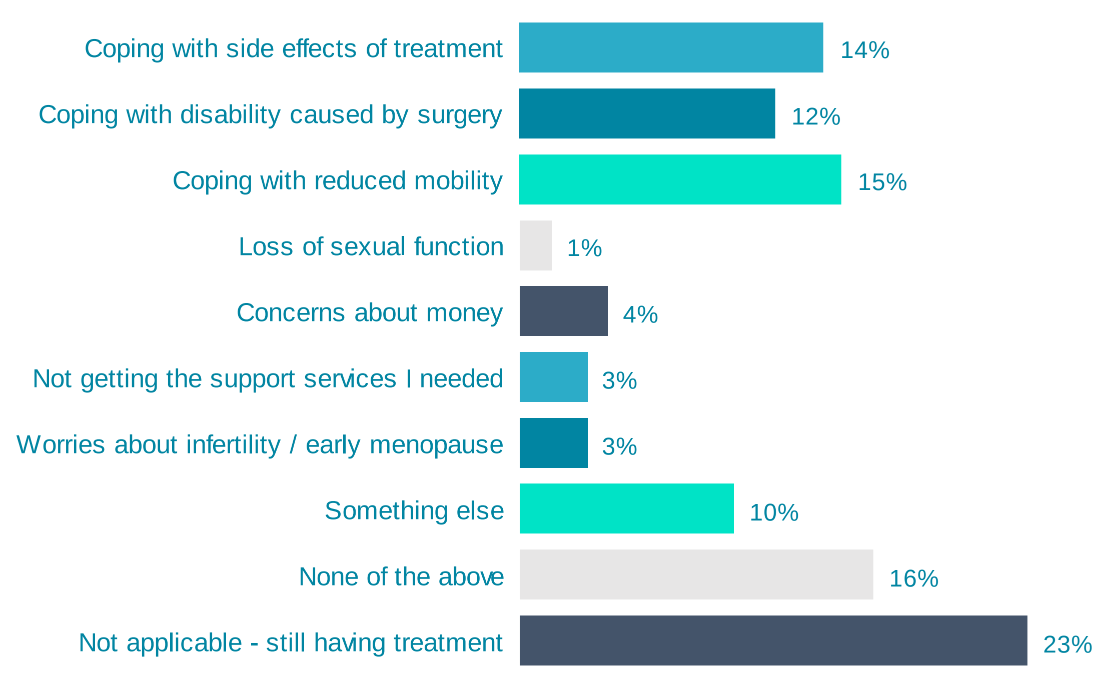
Impact on day to day life after diagnosis and treatment



*From question 36, 16+ questionnaire: After diagnosis and treatment, do any of the following impact your day to day life?*

When respondents were asked, after finishing treatment, what affected them **most** day to day, the most common choices were: coping with reduced mobility (**15%**), coping with side effects of treatment (**14%**) and coping with disability caused by surgery (**12%**). *(Q37, 16+ Questionnaire)*

After finishing treatment, patients were affected the most day to day by:



*From question 37, 16+ questionnaire: When your treatment finished, what affected you the most day to day?*

**10%** chose ‘something else’. This included comments such as:

> *‘I'm most affected by the 'waiting/not knowing' if or when this cancer will return. I was pretty shocked by the high recurrence rate (50-70%) and get annoyed that no-one really understands that, just because the primary tumour has gone, it doesn't mean I'm out of the woods. I can't plan anything more than a few months in advance, and I do worry about it coming back – I need to work to live. I don't have any financial cushion and it really does concern me.’*

> *‘Frustration that the diagnosis hadn't come sooner.’*

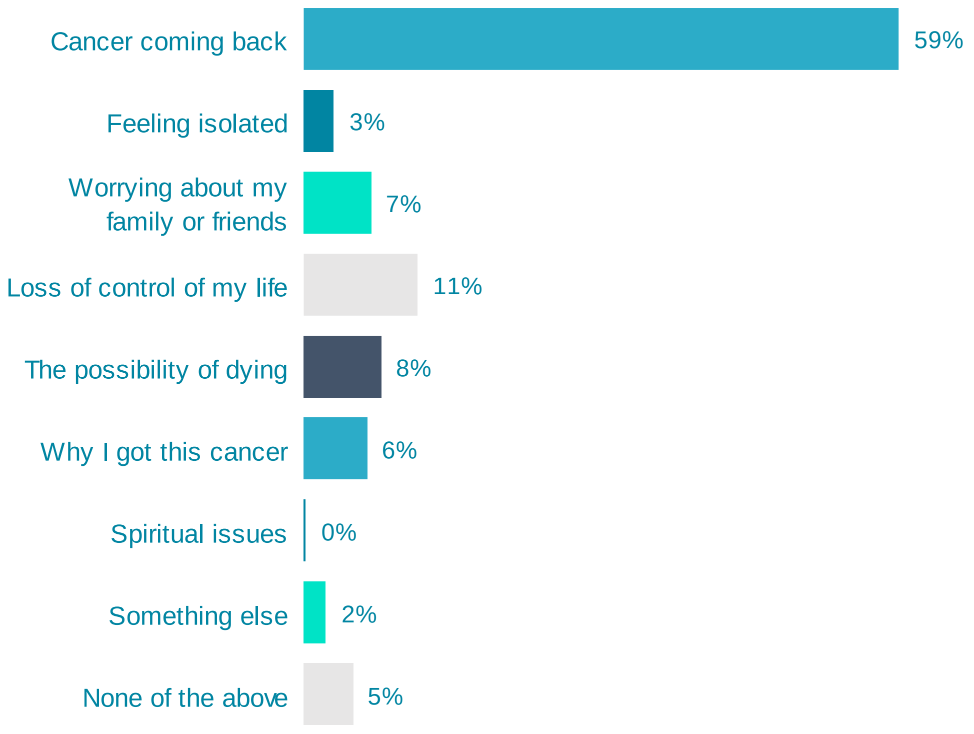
> *‘Coping with pain and drowsiness caused by medication for pain causes me the most difficulty.’*

A full analysis of these comments can be found in the thematic analysis section.

## Biggest worry after finishing treatment

The majority of respondents (**59%**) said, after finishing treatment, they were **most** worried about their cancer coming back. **11%** said they were most worried about loss of control of their life, **8%** said the possibility of dying and **7%** said worrying about their family or friends. *(Q38, 16+ Questionnaire)*

**After finishing treatments, patients were most worried about:**



*From question 38, 16+ questionnaire: When your treatment finished, what were you most worried about?*

**2%** chose ‘something else’. This included comments such as:

> *‘Work, and the fact it stopped me doing my dream job and held me back in my career.’*

> *‘Why my lump was not diagnosed after many tests until the lump was removed which was many months.’*

> *‘Future mobility as post-op results were positive.’*

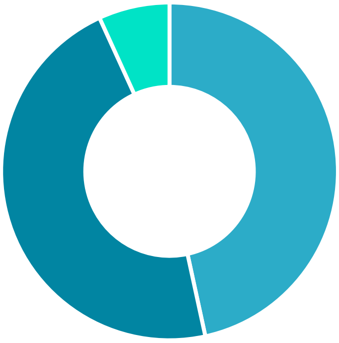
A full analysis of these comments can be found in the thematic analysis section.

## 4.4. Charities and support groups

### Signposting to Sarcoma UK

Half (**47%**) of respondents were told about Sarcoma UK at some point during their care and treatment and half (**47%**) were not. *(Q39, 16+ Questionnaire)*

**Informed about Sarcoma UK**



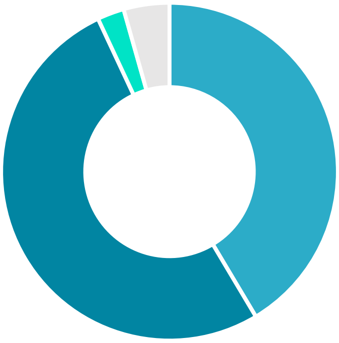
| | | |
|---|---|---|
| 🟦 | Yes | 47% |
| 🟦 | No | 47% |
| 🟩 | Don’t know / can’t remember | 7% |

*From question 39, 16+ questionnaire: At any point during your care and treatment were you told about Sarcoma UK – the national charity for Sarcoma in the UK?*

### Signposting to support groups and charities

Less than half of respondents (**41%**) were told about local cancer support groups and/or charities in the area where they live during their care and treatment. *(Q40, 16+ Questionnaire)*

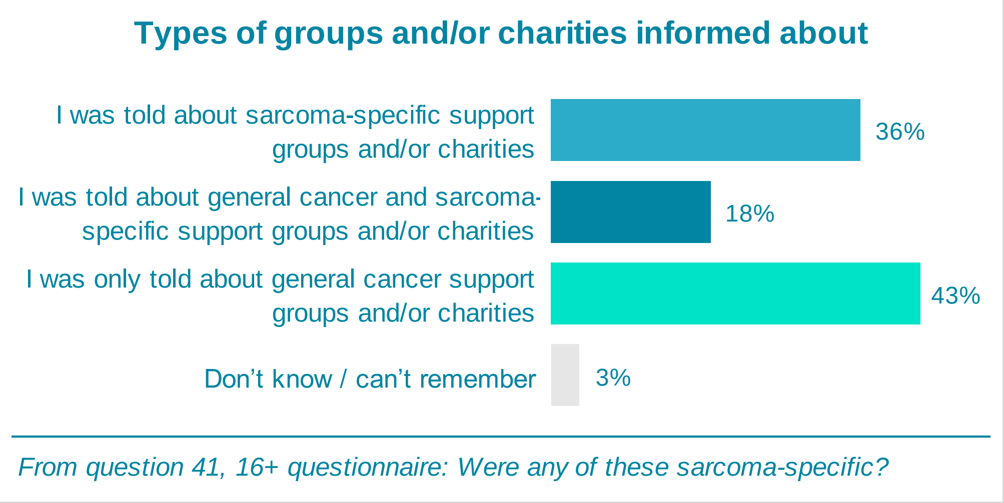
**Informed about local cancer support groups and/or charities in local area**



| | | |
|---|---|---|
| 🟦 | Yes | 41% |
| 🟦 | No | 52% |
| 🟩 | I didn’t want this | 3% |
| ⬜ | Don't know / can't remember | 4% |

*From question 40, 16+ questionnaire: During your care and treatment, were you told about local cancer support groups and / or charities in the area where you live?*

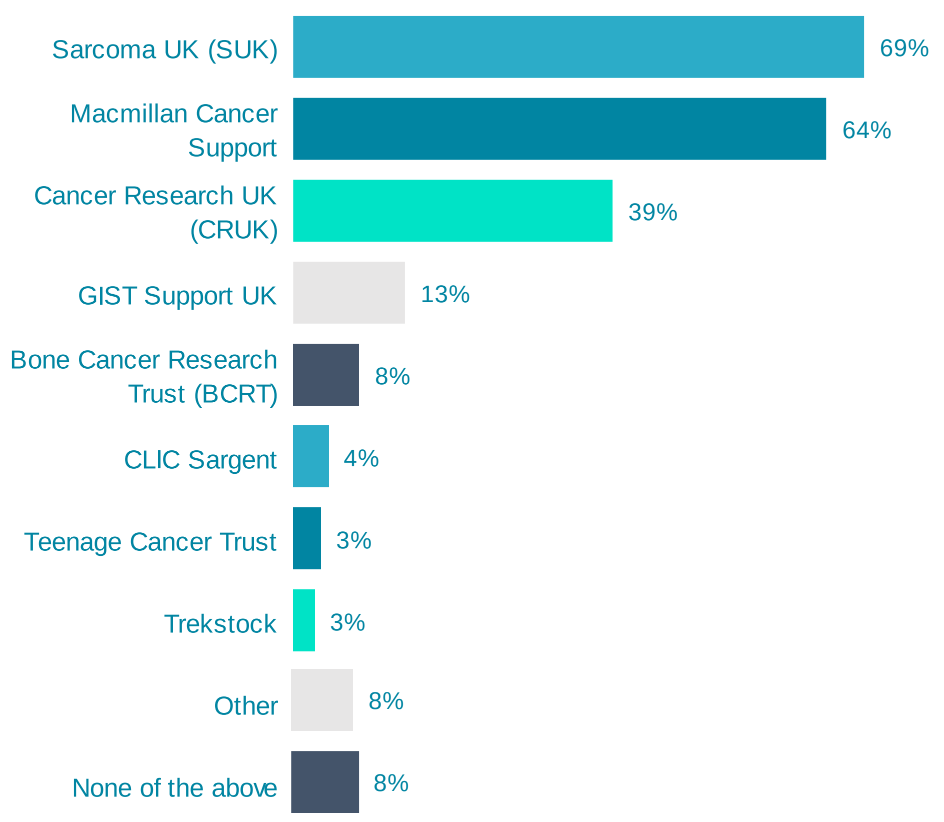
Of those who were told about local support groups and/or charities, nearly half (**43%**) were only told about **general cancer** support groups and/or charities. **36%** were told about **sarcoma-specific** groups and/or charities, and **18%** were told about **both**. *(Q41, 16+ Questionnaire)*



## Charity websites

When participants were asked which national charity websites they had used to get information or support about their sarcoma, the most common choice was Sarcoma UK (**69%**). **64%** said Macmillan Cancer Support, **39%** said Cancer Research UK and **13%** said GIST Support UK. *(Q42, 16+ Questionnaire)*

**Use of national charity websites to get information or support about sarcoma**



*From question 42, 16+ questionnaire: Have you used any of the following national charity websites to get information or support about your sarcoma?*

In addition, when the family and carers were asked which of the websites **they** had used, the most common choices were again Sarcoma UK (**80%**) and Macmillan Cancer Support (**57%**). More in this group selected Teenage Cancer trust (**14%**) and CLIC Sargent (**13%**). *(Q19 Family & Carers Questionnaire)*

# 5. Further analysis

## 5.1. 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:

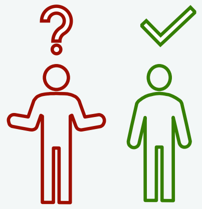
- Q1 Only one-fifth (21%) had heard of sarcoma before their friend/family member was diagnosed.
- Q5 Only half (49%) knew that sarcoma was a type of cancer.
- Q6 Two-thirds (67%) found out about sarcoma online.
- Q7 Over half of respondents went to all appointments with their friend/relative.
- Q9 Three-quarters (75%) said their friend/relative was treated by a specialist sarcoma team.
- Q11 92% of respondents said they provide emotional support to their friend/relative – this was by far the highest percentage from a list which included a range of support/care. The next was on accompanying their friend/relative to appointments (74%).
- Q12 A quarter (24%) provided more than 50 hours of care/support a week.
- Q14 18% said supporting their friend/relative means they are no longer able to work or continue education, with a further 63% saying it had a temporary impact on their ability to work or complete education.
- Q20 Over half (55%) said they had been negatively impacted financially because of the patient’s diagnosis.
- Q21 Nearly two-thirds (65%) said they felt anxious or depressed more often, and a further 28% said they felt anxious or depressed all the time as a result of the patient’s diagnosis.

The infographic on the following page illustrates these findings.

# National Sarcoma Survey 2020

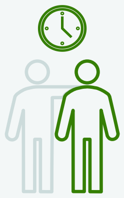
## *Family and Carers Results Summary*

Only **one-fifth** (21%) had heard of sarcoma before their friend/family member was diagnosed



Only **half** (49%) knew that sarcoma was a type of cancer

**Two-thirds** (67%) found out about sarcoma online

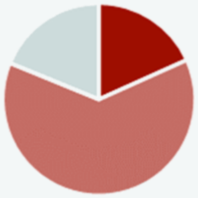


Almost **half** of respondents went to all appointments with their friend/relative

**Three-quarters** (75%) said their friend/relative was treated by a specialist sarcoma team

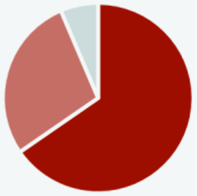
**92%** of respondents said they provide emotional support to their friend/relative

A **quarter** (24%) provided more than 50 hours of care/support a week



**18%** said supporting their friend/relative means they are no longer able to work or continue education, with a further **63%** saying it had a temporary impact on their ability to work or complete education

**Over half** (55%) said they had been negatively impacted financially because of the patient’s diagnosis



Nearly **two-thirds (65%)** said they felt anxious or depressed more often, and a further **28%** said they felt anxious or depressed all of the time as a result of the patient’s diagnosis

## 5.2. 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:

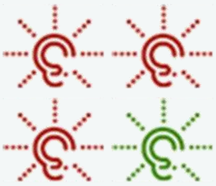
- Q1 Three-quarters (75%) of parents had not heard of sarcoma before their child's diagnosis.
- Q7 Nearly a half (48%) of parents saw a health professional with their child more than 3 times before they were referred for more tests.
- Q13 59% of parents did not know that sarcoma was a cancer until it 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.
- Q23 The side-effects of treatment that were most commonly experienced were changes to skin/hair/nails (86%), loss of appetite (79%) and nausea/vomiting (75%).
- Q24 Nausea and vomiting (46%), followed by pain (39%), were the side effects which parents said had the greatest impact on their child's day-to-day life.
- Q25 61% said their child was cared for in a specialist sarcoma centre (14% were not sure).
- Q26 One-fifth (21%) said they were not given a written care plan for their child.
- Q34 At least a half of respondents said that their child always, often or sometimes felt afraid or scared, sad or angry.
- Q35 One-fifth (20%) of parents said their child would have liked more emotional support.

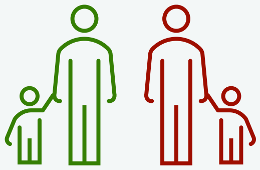
The infographic on the following page illustrates these findings.

# National Sarcoma Survey 2020

## *Parents of Under 16s Results Summary*

**Three-quarters** (75%) of parents had not heard of sarcoma before their child's diagnosis





**Nearly a half** (48%) of parents saw a health professional with their child more than 3 times before they were referred for more tests

**59%** of parents did not know that sarcoma was a cancer until it was explained at their child's diagnosis

**Nearly one-third** of parents (29%) said they were not given enough information when their child was diagnosed

**61%** said their child was cared for in a specialist sarcoma centre

Side-effects of treatment most commonly experienced:
- **86%** Changes to skin/hair/nails
- **79%** Loss of appetite
- **75%** Nausea/vomiting

**One-fifth** (21%) said they were not given a written care plan for their child

Side effects which parents said had the most impact on their child's day-to-day life:
- **46%** Nausea and vomiting
- **39%** Pain

**One-fifth** (20%) of parents said their child would have liked more emotional support

**At least a half** of respondents said that their child always, often or sometimes felt afraid or scared, sad or angry

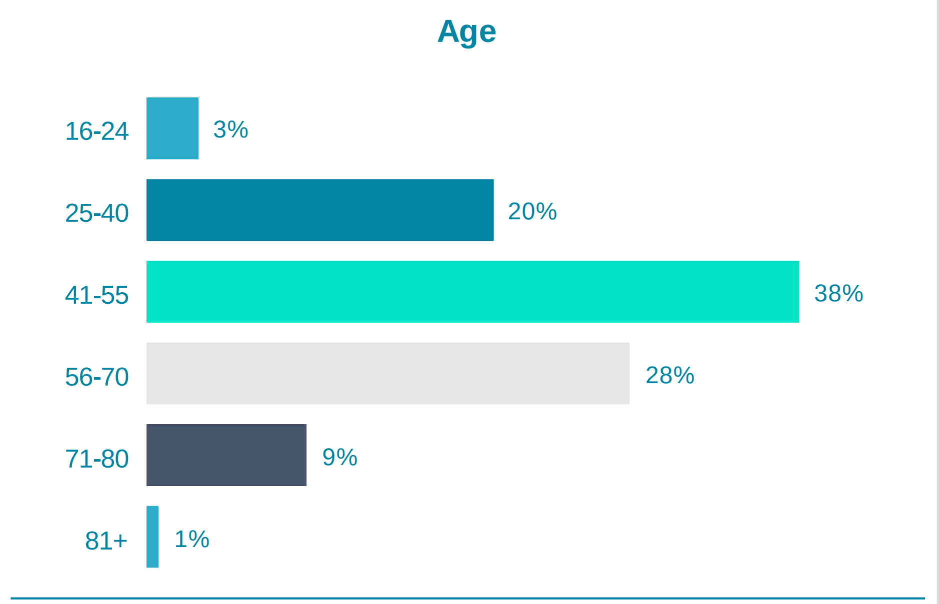
## 5.3. Additional breakdown analysis

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

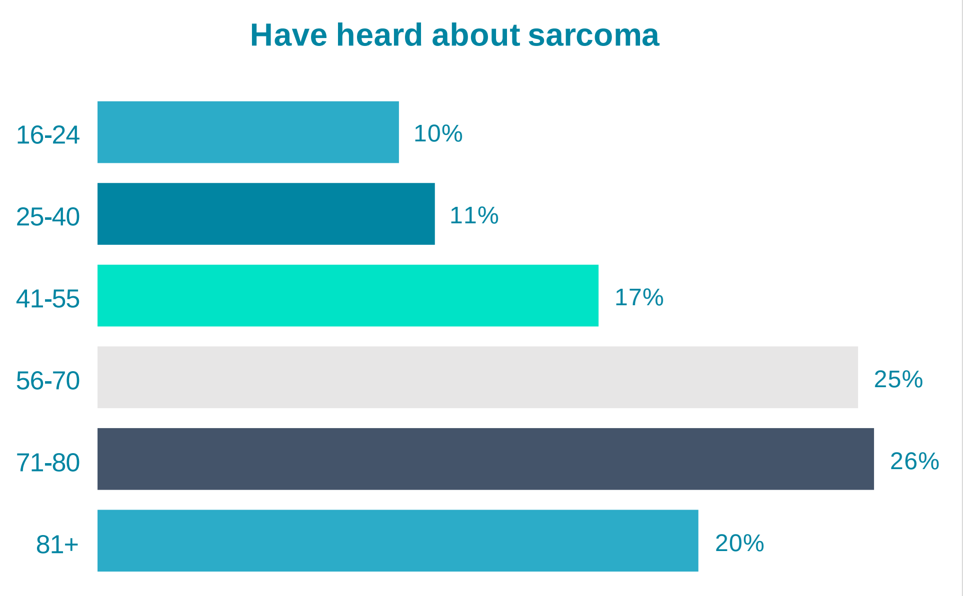


*From question 50, 16+ questionnaire: How old are you?*

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).**



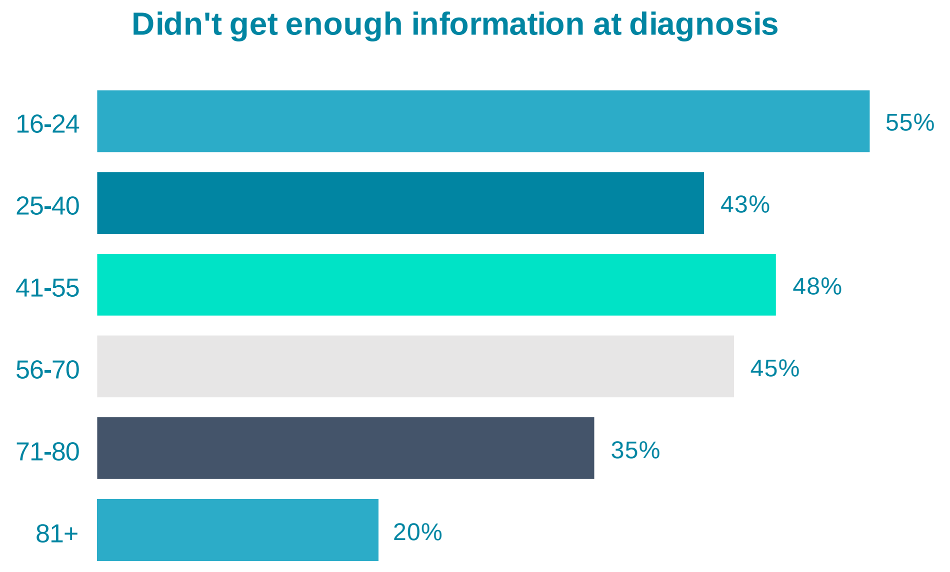
*Respondents who answered "Yes" to question 1, 16+ questionnaire: Had you heard about sarcoma before your diagnosis? - broken down by Q50 "How old are you?*

- 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).**

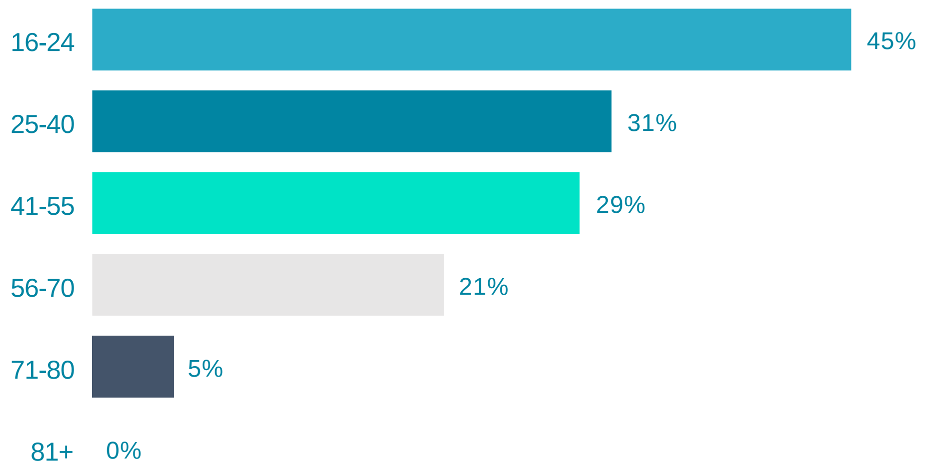


*Respondents who answered "Not Enough" to question 14b, 16+ questionnaire: At diagnosis, how much information were you given? - broken down by Q50 "How old are you?*

- 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).

- **Q31 Younger people were more negative about the extent to which their sarcoma has affected their overall mental health/emotional wellbeing (45% of 16-24 year olds, compared to 21% of 56-70 year olds said ‘severely’).**

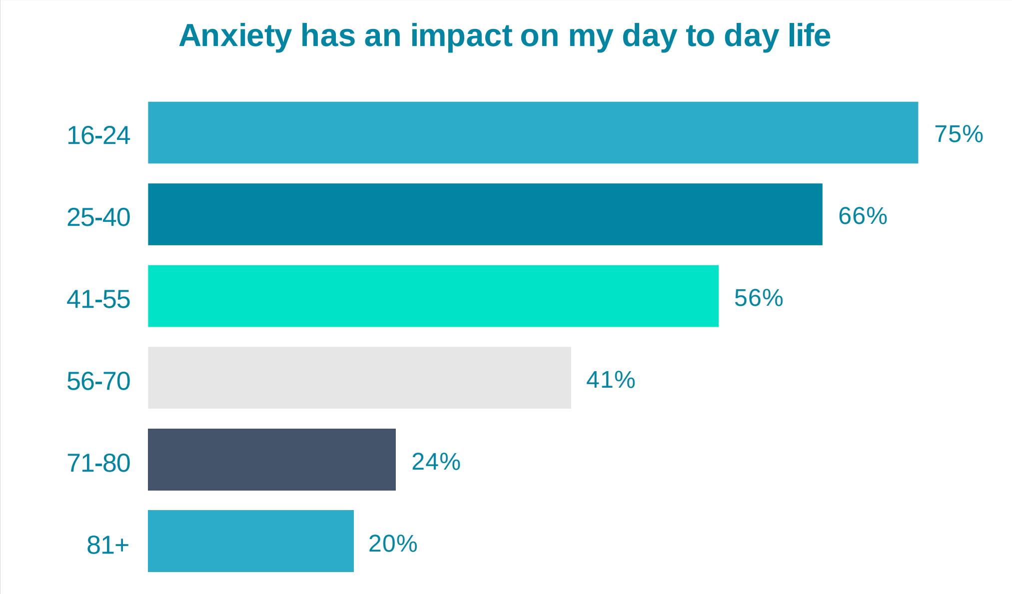

Sarcoma had a severe negative impact on mental health/emotional wellbeing

*Respondents who answered "Severely" to question 31, 16+ questionnaire: To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing? - broken down by Q50 "How old are you?*

- Q32 Older people were more likely to say they did not need emotional support from hospital staff (30% of 71-80 year olds, compared to between 5% and 15% of 16-55 year olds).

- Q34 Older people were more likely to say that the information given to them by the hospital about how their treatment would be followed up was very clear (77% of 71-80 year olds, compared to 62%-65% of 16 to 40 year olds).

- **Q36 Younger people were more likely to say that anxiety impacts their day-to-day life after diagnosis and treatment (75% of 16-24 year olds, compared to 24% of 71-80 year olds).**



*Respondents who answered "Anxiety" to question 36, 16+ questionnaire: After diagnosis and treatment, do any of the following impact your day to day life? - broken down by Q50 "How old are you?*

## 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. Women were also more likely to say they were suffering with anxiety, and that their mental health or emotional wellbeing had been negatively impacted by their diagnosis and treatment.

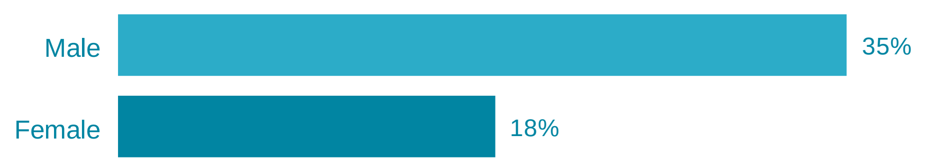
It is important to consider the results here in terms of what this may be telling us over and above simple differences between men and women – for example: whether there are differences in expectations of men and women; how easy men and women find it to talk about, or admit to having emotional support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

**Received accurate diagnosis within a month of first visiting their GP/A&E**



*Respondents who answered "Less than 2 weeks" and "More than 2 weeks but less than 4 weeks" to question 11, 16+ questionnaire: How long after you first visited your GP / A&E did you receive an accurate diagnosis? - broken down by Q49 "Are you male or female?"*

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

Not given enough information at diagnosis

*Respondents who answered "Not enough information" to question 14b, 16+ questionnaire: At diagnosis, how much information were you given? - broken down by Q49 "Are you male or female?"*

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

- Q26 Women were more likely to say they did not have a CNS in charge of their care at any time (18% women, compared to 13% men).

- Q28 Women were less likely to say they were given all the information they needed to help make decisions about their care and treatment (63% women, compared to 73% men).

- **Q31 Women were more likely to say that their diagnosis and treatment of sarcoma has negatively affected their overall mental health/emotional wellbeing (28% women, compared to 19% men saying their mental health/emotional wellbeing was 'severely' affected).**

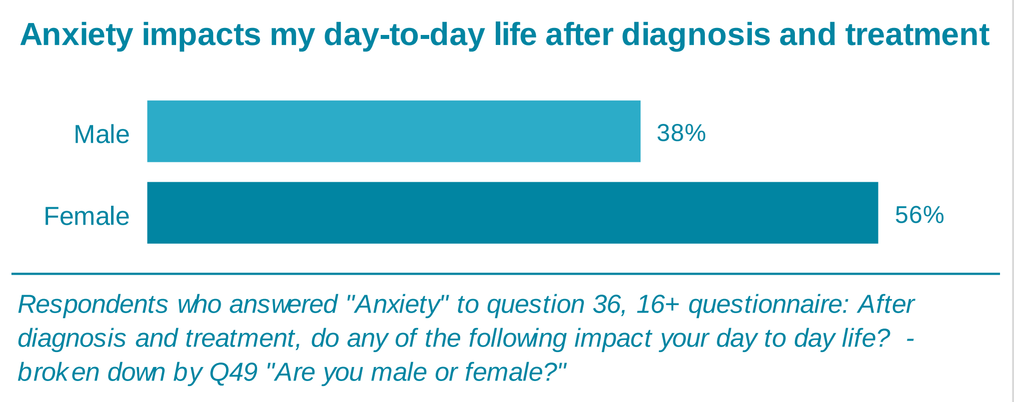
Sarcoma had a severe negative impact on mental health/emotional wellbeing

*Respondents who answered "Severely" to question 31, 16+ questionnaire: To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing? - broken down by Q49 "Are you male or female?"*

- Q32 Women were more likely to say they would have liked more emotional support from hospital staff (44% women, compared to 28% men).

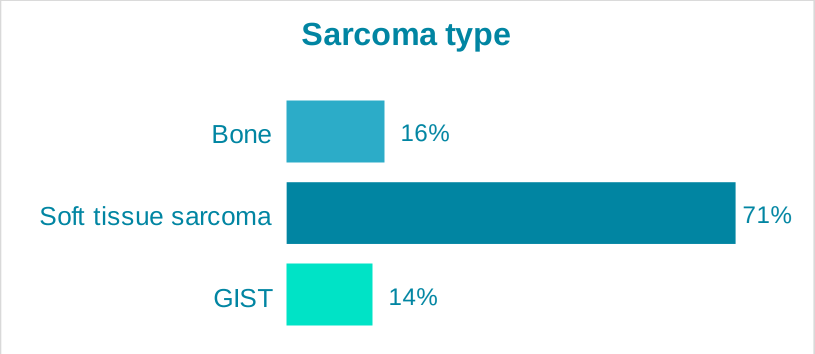
- Q34 Men were more likely to say that the information given to them by the hospital about how their treatment would be followed up was very clear (73% men, compared to 66% women).

- **Q36 Women were more likely to say that anxiety impacts their day-to-day life after diagnosis and treatment (56% women, compared to 38% men), whereas a similar percentage of men and women said depression impacts them (29% respectively).**



*Respondents who answered "Anxiety" to question 36, 16+ questionnaire: After diagnosis and treatment, do any of the following impact your day to day life? - broken down by Q49 "Are you male or female?"*

## Sarcoma Type



*From question 46a, 16+ questionnaire: What type of sarcoma do you have?*

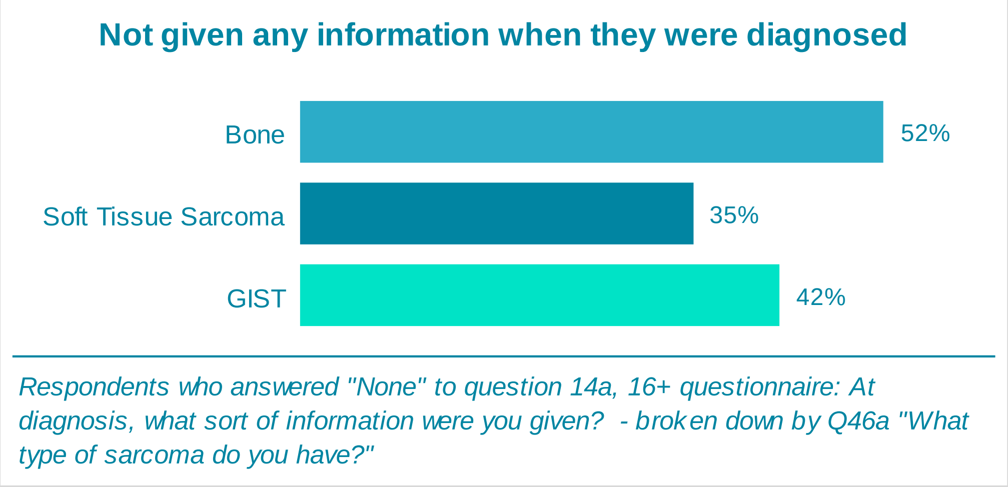
The breakdown by sarcoma type provides detail on the differences between experiences of patients with different types of sarcoma, and enables some comparisons to be drawn. The data shows a mixed picture, with bone sarcoma patients experiencing longer waits for diagnosis and being less likely to say they 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%).**



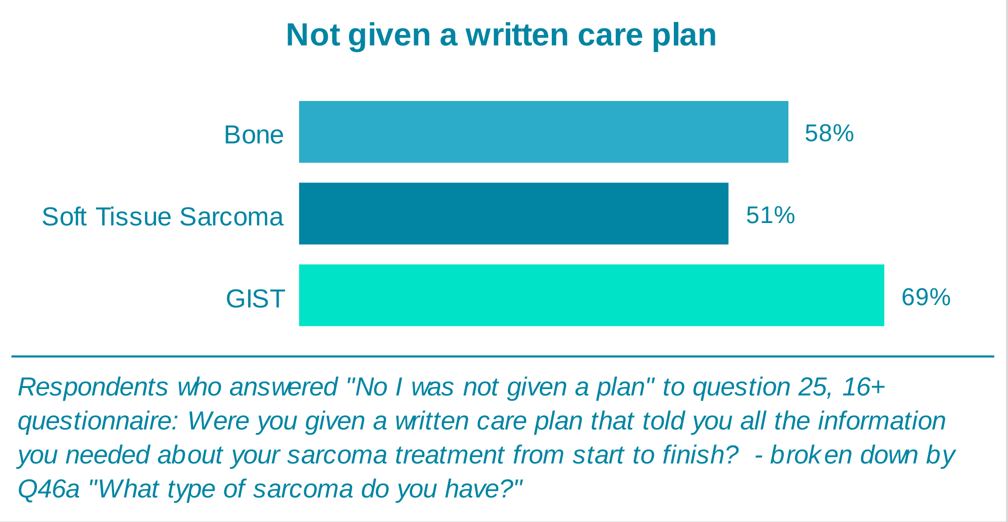
- Q14b GIST patients were more likely to say they had not been given enough information at diagnosis (51%) although the number was also high for both bone (43%) and soft tissue (44%) patients.

- Q22 Bone sarcoma patients were most likely to say they had experienced a range of side effects following treatment – 13 of the 17 symptoms listed were most likely to be experienced by bone sarcoma patients.

- Q23 Bone and soft tissue sarcoma patients were most likely to say that pain was the side effect which has had the greatest impact on their lives (47% and 37% respectively) – while for GIST patients it was daytime fatigue (44%).

- Q24 Bone and soft tissue sarcoma patients were most likely to say they were treated at a specialist sarcoma centre (86% and 84% respectively, compared to 64% GIST).

- **Q25 GIST patients were more likely to say they were not given a written care plan (69%), compared to 58% bone sarcoma and 51% soft tissue sarcoma.**



*Respondents who answered "No I was not given a plan" to question 25, 16+ questionnaire: Were you given a written care plan that told you all the information you needed about your sarcoma treatment from start to finish? - broken down by Q46a "What type of sarcoma do you have?"*

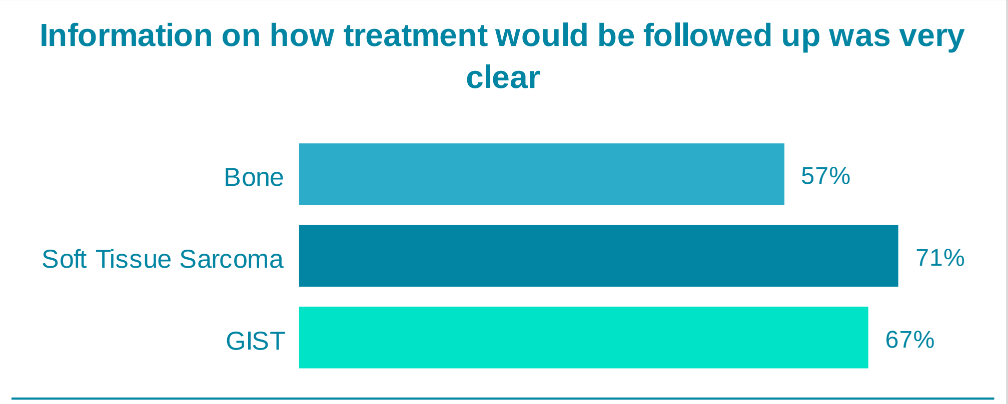
- Q26 Soft tissue sarcoma patients were more likely to say they have a named CNS or key worker (66%) compared to 57% bone sarcoma patients, 51% GIST patients.

- Q28 Bone sarcoma patients were less likely to say they had all the information they needed to help them make decisions about their treatment and care (57%), compared to 68% soft tissue sarcoma patients and 67% GIST 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).

- Q32 GIST patients were least likely to say they had definitely been given the emotional support they needed (9%), compared to 20% bone sarcoma and 18% soft tissue sarcoma.

- **Q34 Bone sarcoma patients were less likely to say that the information they were given on how their treatment would be followed up was very clear (57%), compared to 71% soft tissue and 67% GIST sarcoma.**



*Respondents who answered "Very clear" to question 34, 16+ questionnaire: How clear was the information given to you by the hospital about how your treatment would be followed up? - broken down by Q46a "What type of sarcoma do you have?"*

## Location (England/Scotland comparison)

From question 48, 16+ questionnaire: Where were you treated?

**‘Other’ category includes people who said they were treated somewhere ‘other’ than the UK but also mentioned that they were also treated in the UK in the free text box.**

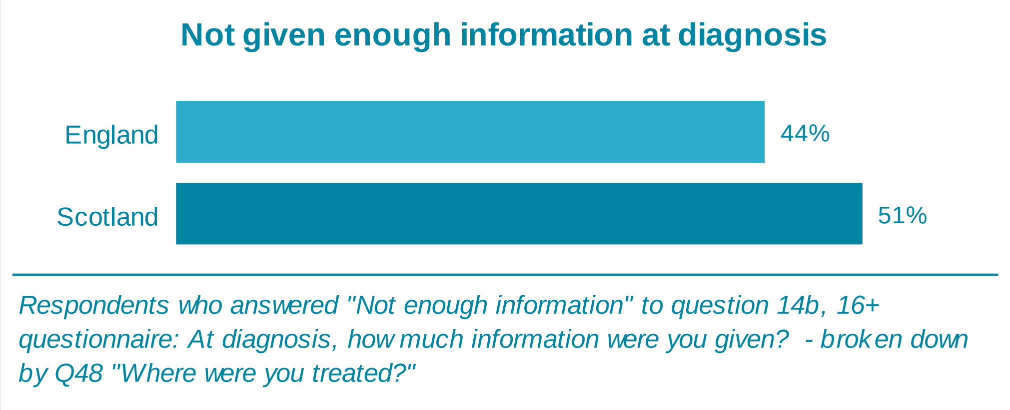
The numbers are lower for Scotland than for England so, when making comparisons, this group must be treated with caution. In addition, Wales and Northern Ireland have not been included in this analysis due to low numbers. The differences in how people in England and Scotland responded did not amount to one group consistently answering more positively or negatively. There were differences in experience around diagnosis, with more people in Scotland diagnosed after only one trip to a healthcare professional and within two weeks of initially presenting. Fewer people in Scotland received information at diagnosis, however they were more likely to have been informed of support groups (although not sarcoma-specific groups).

- Q4 People in Scotland were more likely to go to A&E first (13%, compared to 6% in England) rather than, for example, seeing a GP about their symptoms (73% compared to 84% in England).

- Q11 People in Scotland were more likely to receive an accurate diagnosis within the first two weeks of visiting a healthcare professional about their symptoms (14% compared to 8% in England).

- Q14a People in Scotland were more likely to say that they were not given any information at diagnosis (47% compared to 36% in England).

- **Q14b People in Scotland were more likely to say that they were not given enough information at diagnosis (51% compared to 44% in England).**

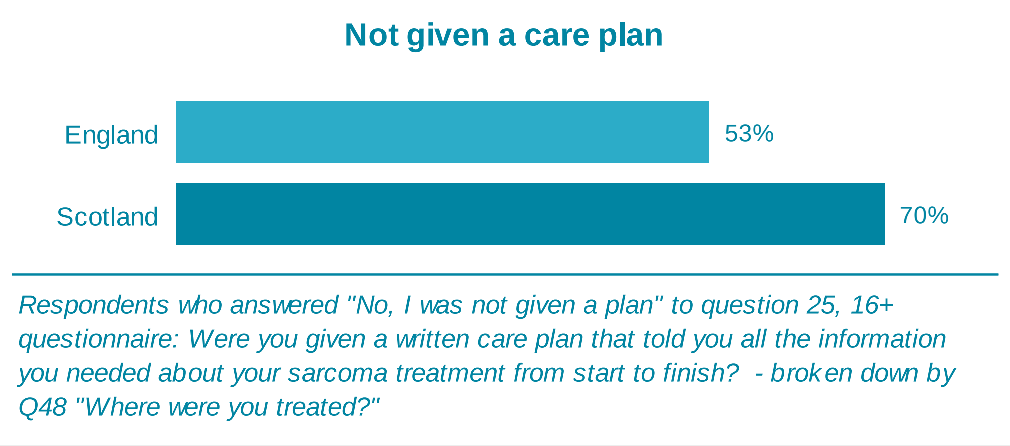


*Respondents who answered "Not enough information" to question 14b, 16+ questionnaire: At diagnosis, how much information were you given? - broken down by Q48 "Where were you treated?"*

- Q21 Respondents in Scotland answered more positively about how easy or difficult it was to travel for their treatment (22% said ‘very easy’, compared to 12% in England).

- Q24 Fewer people in Scotland were treated by a sarcoma specialist team (68%, compared to 83% in England).

- **Q25 People in Scotland were less likely to be given a written care plan that told them all the information they needed about their treatment (70%, compared to 53% in England).**



*Respondents who answered "No, I was not given a plan" to question 25, 16+ questionnaire: Were you given a written care plan that told you all the information you needed about your sarcoma treatment from start to finish? - broken down by Q48 "Where were you treated?"*

- Q29 Fewer people in Scotland than England were invited to take part in any research (67% said no, compared to 47% in England).

## 5.4. 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 (5.3).

The key findings are listed here, and the details of this can be found in appendix A. 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.

### Diagnosis

### 1. The relationship between time to receive an accurate diagnosis and the number of visits to a healthcare professional before being referred (see appendix A, D1)

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). We also considered the relationship between different age groups and time to receive an accurate diagnosis (D2) for particular symptoms, however the numbers were too small to draw any meaningful conclusions.

### Support

### 2. The emotional impact and support given, comparing those who were treated by a sarcoma specialist team to those who were not (see appendix A, S1/S2)

The analysis showed that a patient’s overall mental health and wellbeing was no more or less likely to be negatively affected depending on if they are treated by a sarcoma specialist team (S1). Respondents were equally affected whichever setting they were treated in.

We also asked respondents what affected them when they finished treatment, and compared those who were treated in a sarcoma specialist team to those who were not. We could not compare the responses however as there were far more respondents who had been treated at a sarcoma specialist centre than those who had not, therefore some small numbers for individual response options.

Participants were more likely to be referred to a rehab service if they were treated by a specialist sarcoma cancer team (although as before, the numbers being treated by a non-specialist team were small, so comparison should be treated cautiously). (S2)

### 3. The relationship between various factors and patient anxiety (see appendix A, S3)

Analysis showed that the longer it took for a patient to be diagnosed, the more likely they were to experience anxiety (S3), and that those who found travelling for treatment difficult were also more likely to experience anxiety. However, there was no difference between those patients who had been told about support groups or not – both were equally likely to experience anxiety.

### 4. The relationship between being treated by a specialist sarcoma team and having the likelihood of having a Clinical Nurse Specialist (see appendix A, S4)

Analysis showed that those who were treated by a sarcoma specialist team were more likely to be aware that they had a Clinical Nurse Specialist in charge of their care (S4), although again, the numbers were small for those who were not treated in a specialist team, so comparisons should be treated cautiously.

## Treatment

### 5. How number of hospitals attended impacts day-to-day life (see appendix A, T1)

Analysis showed that generally, people who attended more hospitals for their treatment were more likely to be impacted by pain, mobility issues and fatigue in their day-to-day life (T1). Respondents who had attended more than three hospitals for their treatment were the most likely to be impacted by any of these things (anxiety, insomnia, pain, mobility issues and fatigue.)

### 6. Whether waiting a long time to present impacts overall mental health and wellbeing (see appendix A, C1)

Analysis showed that the extent to which overall mental health and emotional wellbeing is negatively affected does not seem to be impacted by how long people wait to present (C1). However, those respondents who had waited longer to present were more likely to have been impacted by at least one on the following: anxiety, insomnia, pain, mobility issues and fatigue.

The analysis did not show that there were any clear differences in the treatment people had, depending on how long they had taken to present (C3). And again, the extent to which respondents said that their overall mental health and emotional wellbeing is negatively affected does not seem to be impacted by how long people wait to present.

The analysis also looked at whether the time it took to present affected whether patients experienced certain impacts on their day-to-day life once they had finished treatment (such as coping with side effects or reduced mobility). There were no clear messages emerging from this data.

### 7. The impact on those who had to see a healthcare professional more times before being referred (see appendix A, C4)

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 (C4).

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.

### 8. The impact of waiting longer to receive an accurate diagnosis (see appendix A, C5)

The analysis showed that those who waited longer to receive an accurate diagnosis were more likely to have had more than one operation (C5). 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.

### 9. Likelihood of receiving chemotherapy or radiotherapy if treated by a sarcoma specialist team (see appendix A, C6)

Analysis showed that those who were treated by a specialist sarcoma team appear more likely to receive radiotherapy or chemotherapy than those who were not (C6). However, there were small numbers in the group not treated by a specialist sarcoma team, so comparisons should be treated with caution.

### 10. The impact of being given a written care plan (see appendix A, C7)

The analysis looked at whether the likelihood of patients receiving a written care plan affected the kind of treatment they had (an operation, chemotherapy, radiotherapy). There was no clear finding emerging from this.

The analysis also appears to tell us that those who said they had a care plan but it only told them some things and those who said they were not given a care plan were both more likely to say their overall mental health and emotional wellbeing were severely negatively affected.

Finally, the analysis looked at whether those who were given a written care plan were more or less likely to be affected by a number of factors (such as coping with side effects, reduced mobility or disability). However, there were no clear findings emerging from this.

## 5.5. 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.

There were multiple free text opportunities in the questionnaires, and the thematic analysis detailed below is for the following questions:

- 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)*

- When your treatment finished, what affected you the most day to day? 'Something else (please specify)'
  *(Q37 16+ questionnaire)*

- When your treatment finished, what were you most worried about? 'Something else (please specify)'
  *(Q38 16+ questionnaire)*

- What would be the three biggest improvements that could be made to sarcoma services?
  *(Q43 16+ Questionnaire) (Q43 Parents of Under 16s Questionnaire) (Q22 Family and Carers Questionnaire)*

The themes are listed by the number of comments (in descending order), with any miscellaneous and not applicable comments at the end. Example comments are provided for the most common themes.

### 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% |
| **Total** | **981** | **100%** |

### 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% |
| **Total** | **89** | **100%** |

### 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.'*

## When your treatment finished, what affected you the most day to day? ‘Something else (please specify)’ *(Q37 16+ 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:

- **Fear of recurrence** Comments about the uncertainty around long-term health.
- **Coping with other side effects** Comments about coping with side effects (not including tiredness).
- **Anxiety and mental health** Comments about mental health, anxiety and need for support.
- **Work and getting back to normal** Comments about employment and returning to ‘normal’.
- **Tiredness** Comments specifically about fatigue.
- **Feeling left alone** Comments about a lack of follow-up appointments or contact.
- **Frustration with others (including healthcare professionals)** Comments about others’ behaviour – from friends to healthcare professionals.
- **NA / personal information** ‘Not applicable’ comments or factual comments about respondents’ situations, for example when they finished treatment.

There were **75** comments received in total. Of the 75 full comments, **87** individual comments were identified.

| Theme | Count | Percentage |
|---|---:|---:|
| Fear of recurrence | 20 | 23% |
| Coping with other side effects | 17 | 20% |
| Anxiety and mental health | 14 | 16% |
| Work and getting back to normal | 10 | 11% |
| Tiredness | 8 | 9% |
| Feeling left alone | 8 | 9% |
| Frustration with others (including healthcare professionals) | 7 | 8% |
| NA / personal information | 3 | 3% |
| **Total** | **87** | **100%** |

### Fear of recurrence

*‘Not knowing if/when it might metastasise or appear elsewhere.’*

*‘Thinking every ache or pain was a sign it had returned.’*

### Coping with other side effects

*‘Side effects of radiotherapy – fatigue and bowel disturbance.’*

*‘Coping with hearing loss (which was an unexpected side effect of treatment).’*

## When your treatment finished, what were you most worried about? ‘Something else (please specify)’ *(Q38 16+ 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:

- **All / most of the above** Comments stating more than one of the given answer options applied to them.
- **Family** Comments about the impact on family members.
- **Inappropriate follow-up care** Comments about concerns around inadequate follow up.
- **Work** Comments about work concerns.
- **Symptoms** Comments about symptoms (that might indicate something important).
- **Side effects** Comments about the impact of side effects.
- **Miscellaneous**
- **NA / personal information** ‘Not applicable’ comments or factual comments about respondents’ situations.

There were **22** comments received in total. Of the 22 full comments, **24** individual comments were identified.

| **Theme** | **Count** | **Percentage** |
|---|---:|---:|
| All / most of the above | 4 | 17% |
| Family | 3 | 13% |
| Inappropriate follow-up care | 3 | 13% |
| Work | 2 | 8% |
| Symptoms | 2 | 8% |
| Side effects | 2 | 8% |
| Miscellaneous | 2 | 8% |
| NA / personal information | 6 | 25% |
| **Total** | **24** | **100%** |

### Family

*‘Leaving my child without their parent.’*

*‘Family.’*

*‘What would happen to my kids if I pass?’*

### Inappropriate follow-up care

*‘Not receiving appropriate follow up despite being advised that I would need lifelong follow up.’*

*‘No clear plan and seeing a different doctor at every appointment, along with different surgeon.’*

### What would be the three biggest improvements that could be made to sarcoma services? *(Q43 16+ Questionnaire) (Q43 Parents of Under 16s Questionnaire)* (Q22 Family and Carers 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:

- **Information** Comments about more or better information, across a wide variety of topics and points in the journey, including some comments about quality of explanation.
- **Sarcoma awareness – medical professionals** Comments about knowledge and awareness of sarcoma, specifically among medical professionals and often GPs.
- **(Emotional) support** Comments about support, often specifically emotional support.
- **Improved access to (sarcoma-specialist) care and professionals** Comments about more (or closer) sarcoma specialist centres and professionals, and general comments about improving access to care.
- **Communication and organisation of care** Comments about communication, regularity of contact and organisation of care.
- **Quicker / better diagnosis** Comments about an improved diagnosis, including support, information, and communication at diagnosis.
- **Sarcoma awareness – general** Comments about knowledge and awareness of sarcoma (that do not specifically mention medical professionals.)
- **Research / funding** Comments about research and funding, including comments about clinical trials and finding a cure for sarcoma.
- **Referral / speed** Comments about quicker results, waiting lists and immediate referrals.
- **Charities, peer support and groups** Comments about support groups, peer support and charity services.
- **Life with sarcoma** Comments across a range of day-to-day topics – from financial support, to comfier waiting rooms, to nutrition advice.
- **Aftercare** Comments about support after treatment, including emotional support, and getting ‘back to normal’.
- **Information / support specific to children (specific to Parents of Under 16s Questionnaire)** Comments about care, support and information that is specifically for or in relation to children.
- **Bereavement support (specific to Family and Carers Questionnaire)** Comments about support for the bereaved.
- **End-of-life care (specific to Family and Carers Questionnaire)** Comments about improving the experience around the end of a patient’s life.
- **Miscellaneous**
- **N/A**

## What would be the three biggest improvements that could be made to sarcoma services? *(Q43 16+ Questionnaire)*

There were **1228** comments received for the 16+ questionnaire. Of the 1228 full comments, **1391** individual comments were identified.

| **Theme** | **Count** | **Percentage** |
|---|---|---|
| Information | 212 | 15% |
| Sarcoma awareness – medical professionals | 153 | 11% |
| (Emotional) support | 145 | 10% |
| Improved access to (sarcoma-specialist) care and professionals | 138 | 10% |
| Communication and organisation of care | 132 | 9% |
| Quicker / better diagnosis | 122 | 9% |
| Sarcoma awareness – general | 104 | 7% |
| Research / funding | 87 | 6% |
| Referral / speed | 82 | 6% |
| Charities, peer support and groups | 69 | 5% |
| Life with sarcoma | 59 | 4% |
| Aftercare | 45 | 3% |
| Miscellaneous | 26 | 2% |
| N/A | 17 | 1% |
| **Total** | **1391** | **100%** |

### Information

*‘Clear written information and data about your type of sarcoma.’*

*‘More information available at hospital outpatients.’*

*‘Information about side effects from surgery that is realistic and not too optimistic.’*

### Sarcoma awareness: medical professionals

*‘More GP awareness and better training to identify sarcoma.’*

*‘Clinicians’ knowledge and understanding of it.’*

### (Emotional) support

*‘Stronger links to emotional support from the beginning.’*

*‘Access to support services.’*

*‘More support services – emotionally and physically.’*

## What would be the three biggest improvements that could be made to sarcoma services? *(Q43 Parents of Under 16s Questionnaire)*

There were **107** comments received for the parents' questionnaire. Of the 107 full comments, **118** individual comments were identified.

| **Theme** | **Count** | **Percentage** |
|---|---|---|
| Research / funding | 20 | 17% |
| Information | 19 | 16% |
| Sarcoma awareness – medical professionals | 15 | 13% |
| Improved access to (sarcoma-specialist) care and professionals | 15 | 13% |
| Sarcoma awareness – general | 11 | 9% |
| Charities, peer support and groups | 9 | 8% |
| (Emotional) support | 6 | 5% |
| Information / support specific to children | 6 | 5% |
| Referral / speed | 4 | 3% |
| Communication and organisation of care | 3 | 3% |
| Life with sarcoma | 2 | 2% |
| Aftercare | 2 | 2% |
| Quicker / better diagnosis | 1 | 1% |
| Miscellaneous | 5 | 4% |
| N/A | 0 | 0% |
| **Total** | **118** | **100%** |

### Research / funding

*'More research into new treatments for childhood sarcoma.'*

*'Lobby for funds for research into this rare cancer.'*

*'More research into sarcoma and kinder treatments.'*

### Information

*'More detailed info to reduce the need to Google.'*

*'More information about what it actually is and how it forms.'*

### Sarcoma awareness: medical professionals

*'Make consultants more aware of sarcoma. Even though it is rare, it happens, and the diagnosis takes far too long. Every day matters.'*

*'Make sure that all GPs are aware of the golf ball campaign.'*

## What would be the three biggest improvements that could be made to sarcoma services? *(Q22 Family and Carers Questionnaire)*

There were **804** comments received for the family and carers' questionnaire. Of the 804 full comments, **903** individual comments were identified.

| **Theme** | **Count** | **Percentage** |
|---|---|---|
| (Emotional) support | 100 | 11% |
| Research / funding | 98 | 11% |
| Sarcoma awareness – medical professionals | 95 | 11% |
| Information | 94 | 10% |
| Sarcoma awareness – general | 90 | 10% |
| Improved access to (sarcoma-specialist) care and professionals | 88 | 10% |
| Quicker / better diagnosis | 80 | 9% |
| Communication and organisation of care | 71 | 8% |
| Life with sarcoma | 58 | 6% |
| Charities, peer support and groups | 44 | 5% |
| Referral / speed | 40 | 4% |
| Bereavement support | 10 | 1% |
| Aftercare | 8 | 1% |
| End of life care | 5 | 1% |
| Miscellaneous | 11 | 1% |
| N/A | 11 | 1% |
| **Total** | **903** | **100%** |

### (Emotional) support

*'Support to the patient and the family.'*

*'Support and counselling service for patients (children and young people especially) and their family members.'*

### Research / funding

*'For the government to acknowledge sarcoma, and put funding into more research and resources.'*

*'Fund more research into diagnosis and treatment for sarcoma.'*

### Sarcoma awareness: medical professionals

*'For GPs to be more aware of and knowledgeable about sarcoma and access to specialist sarcoma teams.'*

*'Publicise awareness – such as the 'golf ball initiative' – to health professionals, including non-GPs.'*

# 6. Conclusions

Ahead of this survey, many people affected by sarcoma made it clear that their experience of care in the UK 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.

Despite attempts to ensure that all sarcoma patients are treated at a specialist centre, for a significant number of people this is not the case. Drawing a comparison to the 2015 National Sarcoma Survey, the proportion of people treated outside of these centres has grown.

The effect of sarcoma on the psychological wellbeing of both patients and their support networks should not be underestimated – with almost all patients and carers responding to our survey saying that there was a negative impact on their mental health and wellbeing. Despite this, not enough said they were offered formal support.

Another clear area for improvement is a dissatisfaction in the level of information given to patients. Getting the right information at the right time can help to make better informed decisions about treatment, and can support mental wellbeing at such a difficult time. Information was the most popular choice when the 16+ group were asked what the biggest improvements to sarcoma services would be. Counselling and support groups can provide patients with someone to talk to from outside their support network. However, less than half of respondents were told about local support groups and, of these, only around half again were told about sarcoma-specific groups.

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

# 7. Appendices

## 7.1. Appendix A – Cross tabulation of questions for further analysis

### A1. Diagnosis (D)

#### D1. Q11 by Q7

| | ***Q7 Before you were referred for further tests, how many times did you see a healthcare professional about the symptoms you had?*** | **Q11 How long after you first visited your GP / A&E did you receive an accurate diagnosis?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | | **More than 4 weeks** | |
| | **Base** | 94 | | 194 | | 114 | | 86 | | 113 | | 507 | |
| | **Response Code** | 2 | | 3 | | 4 | | 5 | | 6 | | 3-6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 2 | I saw a healthcare professional once | 47 | 50% | 66 | 34% | 25 | 22% | 9 | 10% | 7 | 6% | 107 | 21% |
| 3 | I saw a healthcare professional twice | 7 | 7% | 47 | 24% | 22 | 19% | 18 | 21% | 10 | 9% | 97 | 19% |
| 4 | I saw a healthcare professional 3 or 4 times | 8 | 9% | 23 | 12% | 34 | 30% | 31 | 36% | 30 | 27% | 118 | 23% |
| 5 | I saw a healthcare professional 5 or more times | 1 | 1% | 6 | 3% | 15 | 13% | 19 | 22% | 58 | 51% | 98 | 19% |
| | **Saw HCP three times or more** | 9 | 10% | 29 | 15% | 49 | 43% | 50 | 58% | 88 | 78% | 216 | 43% |

## D2. Q2a by Q3 & age bands

| | *Q2a*<br>*What were the main health problems or symptoms that first made you think something was wrong? - Painless lump* | Q50 How old are you? | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 16-24 | | 25-40 | | 41-55 | | 56-70 | | 71-80 | | 81+ | |
| | **Base** | 20 | | 134 | | 252 | | 187 | | 62 | | 5 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| | **Q3 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Less than 2 weeks | 4 | 20% | 23 | 17% | 28 | 11% | 12 | 6% | 8 | 13% | 0 | 0% |
| 2 | More than 2 weeks but less than 4 weeks | 3 | 15% | 5 | 4% | 27 | 11% | 15 | 8% | 6 | 10% | 1 | 20% |
| 3 | More than 4 weeks but less than 3 months | 1 | 5% | 11 | 8% | 18 | 7% | 10 | 5% | 6 | 10% | 0 | 0% |
| 4 | More than 3 months but less than 6 months | 0 | 0% | 3 | 2% | 6 | 2% | 4 | 2% | 1 | 2% | 0 | 0% |
| 5 | More than 6 months but less than a year | 0 | 0% | 3 | 2% | 9 | 4% | 5 | 3% | 1 | 2% | 0 | 0% |
| 6 | More than a year | 2 | 10% | 3 | 2% | 4 | 2% | 1 | 1% | 1 | 2% | 0 | 0% |

## D2. Q2b by Q3 & age bands

| | ***Q2b*** ***What were the main health problems or symptoms that first made you think something was wrong? - Painful lump*** | **Q50 How old are you?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 16-24 | | 25-40 | | 41-55 | | 56-70 | | 71-80 | | 81+ | |
| | **Base** | 20 | | 134 | | 252 | | 187 | | 62 | | 5 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| | **Q3 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Less than 2 weeks | 1 | 5% | 10 | 7% | 15 | 6% | 4 | 2% | 1 | 2% | 1 | 20% |
| 2 | More than 2 weeks but less than 4 weeks | 0 | 0% | 4 | 3% | 8 | 3% | 11 | 6% | 0 | 0% | 0 | 0% |
| 3 | More than 4 weeks but less than 3 months | 0 | 0% | 5 | 4% | 12 | 5% | 5 | 3% | 3 | 5% | 0 | 0% |
| 4 | More than 3 months but less than 6 months | 0 | 0% | 4 | 3% | 4 | 2% | 3 | 2% | 0 | 0% | 0 | 0% |
| 5 | More than 6 months but less than a year | 0 | 0% | 3 | 2% | 4 | 2% | 1 | 1% | 1 | 2% | 0 | 0% |
| 6 | More than a year | 1 | 5% | 3 | 2% | 5 | 2% | 1 | 1% | 0 | 0% | 0 | 0% |

## D2. Q2c by Q3 & age bands

| ***Q2c***<br>***What were the main health problems or symptoms that first made you think something was wrong? - Lump increasing in size*** | **Q50 How old are you?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 16-24 | | 25-40 | | 41-55 | | 56-70 | | 71-80 | | 81+ | |
| **Base** | 20 | | 134 | | 252 | | 187 | | 62 | | 5 | |
| **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| **Q3 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 Less than 2 weeks | 2 | 10% | 18 | 13% | 20 | 8% | 4 | 2% | 4 | 6% | 1 | 20% |
| 2 More than 2 weeks but less than 4 weeks | 0 | 0% | 4 | 3% | 11 | 4% | 14 | 7% | 4 | 6% | 1 | 20% |
| 3 More than 4 weeks but less than 3 months | 0 | 0% | 9 | 7% | 13 | 5% | 10 | 5% | 6 | 10% | 0 | 0% |
| 4 More than 3 months but less than 6 months | 0 | 0% | 5 | 4% | 5 | 2% | 1 | 1% | 1 | 2% | 0 | 0% |
| 5 More than 6 months but less than a year | 0 | 0% | 3 | 2% | 7 | 3% | 2 | 1% | 0 | 0% | 0 | 0% |
| 6 More than a year | 2 | 10% | 5 | 4% | 6 | 2% | 5 | 3% | 0 | 0% | 0 | 0% |

## D2. Q2d by Q3 & age bands

| | *Q2d What were the main health problems or symptoms that first made you think something was wrong? - New lump in the place where another lump was removed before* | **Q50 How old are you?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 16-24 | | 25-40 | | 41-55 | | 56-70 | | 71-80 | | 81+ | |
| | **Base** | 20 | | 134 | | 252 | | 187 | | 62 | | 5 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| | **Q3 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Less than 2 weeks | 0 | 0% | 2 | 1% | 1 | 0% | 1 | 1% | 0 | 0% | 0 | 0% |
| 2 | More than 2 weeks but less than 4 weeks | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% |
| 3 | More than 4 weeks but less than 3 months | 0 | 0% | 0 | 0% | 1 | 0% | 0 | 0% | 1 | 2% | 0 | 0% |
| 4 | More than 3 months but less than 6 months | 0 | 0% | 1 | 1% | 0 | 0% | 1 | 1% | 0 | 0% | 0 | 0% |
| 5 | More than 6 months but less than a year | 0 | 0% | 1 | 1% | 1 | 0% | 1 | 1% | 0 | 0% | 0 | 0% |
| 6 | More than a year | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% |

## D2. Q2e by Q3 & age bands

| | *Q2e*<br>*What were the main health problems or symptoms that first made you think something was wrong? - Bone pain* | Q50 How old are you? | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 16-24 | | 25-40 | | 41-55 | | 56-70 | | 71-80 | | 81+ | |
| | **Base** | 20 | | 134 | | 252 | | 187 | | 62 | | 5 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| | **Q3 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Less than 2 weeks | 1 | 5% | 2 | 1% | 2 | 1% | 2 | 1% | 0 | 0% | 0 | 0% |
| 2 | More than 2 weeks but less than 4 weeks | 0 | 0% | 4 | 3% | 5 | 2% | 2 | 1% | 1 | 2% | 0 | 0% |
| 3 | More than 4 weeks but less than 3 months | 1 | 5% | 5 | 4% | 10 | 4% | 4 | 2% | 0 | 0% | 0 | 0% |
| 4 | More than 3 months but less than 6 months | 0 | 0% | 4 | 3% | 1 | 0% | 2 | 1% | 1 | 2% | 0 | 0% |
| 5 | More than 6 months but less than a year | 0 | 0% | 2 | 1% | 6 | 2% | 0 | 0% | 0 | 0% | 0 | 0% |
| 6 | More than a year | 1 | 5% | 4 | 3% | 3 | 1% | 1 | 1% | 0 | 0% | 0 | 0% |

## A2. Support (S)

### S1. Q24 by Q31 (also C6)

| | *Q31*<br>*To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing?* | **Q24 Were you treated by a specialist sarcoma cancer team?** | | | |
|---|---|---|---|---|---|
| | | Yes | | No | |
| | **Base** | 527 | | 87 | |
| | **Response Code** | 1 | | 2 | |
| | **Response Options** | **n** | **%** | **n** | **%** |
| 1 | Severely | 127 | 24% | 20 | 23% |
| 2 | To some extent | 233 | 44% | 44 | 51% |
| 3 | Slightly | 115 | 22% | 13 | 15% |
| 1-3 | Had negative impact | 475 | 90% | 77 | 89% |
| 4 | Not at all | 50 | 9% | 10 | 11% |

## S1. Q24 by Q37 (also C6)

***Q37***

***When your treatment finished, what affected you the most day to day?***

| | | Q24 Were you treated by a specialist sarcoma cancer team? | | | |
|---|---|---|---|---|---|
| | | Yes | | No | |
| | **Base** | 527 | | 87 | |
| | **Response Code** | 1 | | 2 | |
| | **Response Options** | **n** | **%** | **n** | **%** |
| 1 | Coping with side effects of treatment | 69 | 13% | 11 | 13% |
| 2 | Coping with disability caused by surgery | 66 | 13% | 4 | 5% |
| 3 | Coping with reduced mobility | 81 | 15% | 6 | 7% |
| 4 | Loss of sexual function | 4 | 1% | 5 | 6% |
| 5 | Concerns about money | 23 | 4% | 1 | 1% |
| 6 | Not getting the support services I needed | 9 | 2% | 5 | 6% |
| 7 | Worries about infertility / early menopause | 14 | 3% | 2 | 2% |
| 8 | Something else | 45 | 9% | 12 | 14% |
| 1-8 | One of these affected me most | 311 | 59% | 46 | 53% |
| 9 | None of the above | 77 | 15% | 19 | 22% |

## S2. Q24 by Q33

| | ***Q33***<br>***Were you referred to any of the following rehab services?*** | **Q24 Were you treated by a specialist sarcoma cancer team?** | | | |
|---|---|---|---|---|---|
| | | Yes | | No | |
| | **Base** | 527 | | 87 | |
| | **Response Code** | 1 | | 2 | |
| | **Response Options** | **n** | **%** | **n** | **%** |
| 1 | Physiotherapy | 215 | 41% | 14 | 16% |
| 1 | Occupational Therapy | 73 | 14% | 0 | 0% |
| 1 | Mobility assistance | 34 | 6% | 2 | 2% |
| 1 | Nutrition / Dietician | 63 | 12% | 8 | 9% |
| 1 | Emotional support (e.g. counselling) | 94 | 18% | 10 | 11% |
| 1 | Other | 27 | 5% | 3 | 3% |
| 1 | No | 189 | 36% | 54 | 62% |

## S3. Q36a by Q11

| *Q36a After diagnosis and treatment, do any of the following impact your day to day life?* | **Q11 How long after you first visited your GP / A&E did you receive an accurate diagnosis?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | |
| **Base** | 54 | | 94 | | 194 | | 114 | | 86 | | 113 | |
| **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 Anxiety | 20 | 37% | 42 | 45% | 101 | 52% | 55 | 48% | 47 | 55% | 71 | 63% |

## S3. Q36a by Q21

| *Q36a After diagnosis and treatment, do any of the following impact your day to day life?* | | **Q21 How easy or difficult has it been to travel for your treatment?** | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Very easy | | Quite easy | | Neither easy nor difficult | | Quite difficult | | Very difficult | |
| | **Base** | 88 | | 213 | | 158 | | 151 | | 41 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Anxiety | 35 | 40% | 94 | 44% | 79 | 50% | 96 | 64% | 29 | 71% |

## S3. Q36a by Q40

| | *Q36a After diagnosis and treatment, do any of the following impact your day to day life?* | **Q40 During your care and treatment, were you told about local cancer support groups and / or charities in the area where you live?** | | | | | |
|---|---|---|---|---|---|---|---|
| | | Yes | | No | | I didn't want this information | |
| | **Base** | 273 | | 340 | | 17 | |
| | **Response Code** | 1 | | 2 | | 3 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Anxiety | 136 | 50% | 177 | 52% | 8 | 47% |

## S4. Q46a by Q24 & Q26 – Option 1

| | | Q24 Were you treated by a specialist sarcoma cancer team? | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Yes | | | | | | No | | | | | |
| | **Base** | 527 | | | | | | 87 | | | | | |
| | **Response Code** | 1 | | | | | | 2 | | | | | |
| | ***Q26***<br>*Were you aware of who the Clinical Nurse Specialist (CNS) in charge of your care was? (They may have been called a keyworker)* | Q46a What type of sarcoma do you have? | | | | | | | | | | | |
| | | Bone | | Soft tissue sarcoma | | GIST | | Bone | | Soft tissue sarcoma | | GIST | |
| | **Base** | 85 | | 372 | | 55 | | 8 | | 52 | | 21 | |
| | **Response Code** | 1 | | 2 | | 3 | | 1 | | 2 | | 3 | |
| | **Response Options** | n | % | n | % | n | % | n | % | n | % | n | % |
| 1 | Yes, I was aware | 54 | 64% | 265 | 71% | 36 | 65% | 2 | 25% | 21 | 40% | 5 | 24% |
| 2 | I was aware of a CNS for part of my treatment, but not all | 10 | 12% | 37 | 10% | 3 | 5% | 2 | 25% | 8 | 15% | 2 | 10% |
| 3 | I did not have a CNS in charge of my care at any time | 14 | 16% | 36 | 10% | 4 | 7% | 4 | 50% | 17 | 33% | 10 | 48% |

## S4. Q46a (bone sarcoma) by Q24 & Q26 – Option 2

| | ***Q46a***<br>*What type of sarcoma do you have? - Bone* | **Q26 Were you aware of who the Clinical Nurse Specialist (CNS) in charge of your care was? (They may have been called a keyworker)** | | | | | |
|---|---|---|---|---|---|---|---|
| | | Yes, I was aware | | I was aware of a CNS for part of my treatment, but not all | | I did not have a CNS in charge of my care at any time | |
| | **Base** | 410 | | 68 | | 106 | |
| | **Response Code** | 1 | | 2 | | 3 | |
| | **Q24 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Treated by a specialist sarcoma cancer team | 54 | 13% | 10 | 15% | 14 | 13% |
| 2 | Not treated by a specialist sarcoma cancer team | 2 | 0% | 2 | 3% | 4 | 4% |

## S4. Q46a (soft tissue sarcoma) by Q24 & Q26 – Option 2

| | ***Q46a***<br>*What type of sarcoma do you have? - Soft tissue sarcoma* | **Q26 Were you aware of who the Clinical Nurse Specialist (CNS) in charge of your care was? (They may have been called a keyworker)** | | | | | |
|---|---|---|---|---|---|---|---|
| | | Yes, I was aware | | I was aware of a CNS for part of my treatment, but not all | | I did not have a CNS in charge of my care at any time | |
| | **Base** | 410 | | 68 | | 106 | |
| | **Response Code** | 1 | | 2 | | 3 | |
| | **Q24 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Treated by a specialist sarcoma cancer team | 265 | 65% | 37 | 54% | 36 | 34% |
| 2 | Not treated by a specialist sarcoma cancer team | 21 | 5% | 8 | 12% | 17 | 16% |

## S4. Q46a (GIST) by Q24 & Q26 – Option 2

| ***Q46a***<br>*What type of sarcoma do you have? - GIST* | **Q26 Were you aware of who the Clinical Nurse Specialist (CNS) in charge of your care was? (They may have been called a keyworker)** | | | | | |
|---|---|---|---|---|---|---|
| | Yes, I was aware | | I was aware of a CNS for part of my treatment, but not all | | I did not have a CNS in charge of my care at any time | |
| **Base** | 410 | | 68 | | 106 | |
| **Response Code** | 1 | | 2 | | 3 | |
| **Q24 Response Options** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 Treated by a specialist sarcoma cancer team | 36 | 9% | 3 | 4% | 4 | 4% |
| 2 Not treated by a specialist sarcoma cancer team | 5 | 1% | 2 | 3% | 10 | 9% |

# A3. Treatment (T)

## T1. Q16 by Q36

| | *Q36 After diagnosis and treatment, do any of the following impact your day to day life?* | **Q16 How many hospitals have you attended for treatment for your sarcoma?** | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | One | | Two | | Three | | More than three | |
| | **Base** | 187 | | 283 | | 122 | | 66 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Anxiety | 93 | 50% | 143 | 51% | 60 | 49% | 39 | 59% |
| 1 | Insomnia | 47 | 25% | 64 | 23% | 33 | 27% | 23 | 35% |
| 1 | Pain | 58 | 31% | 109 | 39% | 55 | 45% | 32 | 48% |
| 1 | Mobility Issues | 53 | 28% | 98 | 35% | 50 | 41% | 29 | 44% |
| 1 | Fatigue | 86 | 46% | 140 | 49% | 75 | 61% | 42 | 64% |
| 1 | At least one of these has an impact | 143 | 76% | 232 | 82% | 104 | 85% | 56 | 85% |
| 1 | None of the above | 43 | 23% | 47 | 17% | 17 | 14% | 10 | 15% |

## A4. Additional crosstabulations (C)

### C1. Q3 by Q31

| | *Q31 To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing?* | Q3 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? | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | **Less than 2 weeks** | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | | **More than 2 weeks** | |
| | **Base** | 214 | | 132 | | 142 | | 48 | | 47 | | 48 | | 631 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 2-6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Severely | 54 | 25% | 33 | 25% | 31 | 22% | 10 | 21% | 16 | 34% | 13 | 27% | 157 | 25% |
| 2 | To some extent | 97 | 45% | 49 | 37% | 72 | 51% | 23 | 48% | 15 | 32% | 27 | 56% | 283 | 45% |
| 3 | Slightly | 43 | 20% | 33 | 25% | 24 | 17% | 11 | 23% | 12 | 26% | 5 | 10% | 128 | 20% |
| 1-3 | Has some negative effect | 194 | 91% | 115 | 87% | 127 | 89% | 44 | 92% | 43 | 91% | 45 | 94% | 568 | 90% |
| 4 | Not at all | 20 | 9% | 17 | 13% | 14 | 10% | 4 | 8% | 3 | 6% | 2 | 4% | 60 | 10% |

## C1. Q3 by Q36

| | *Q36*<br>*After diagnosis and treatment, do any of the following impact your day to day life?* | Q 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? | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | | More than 2 weeks | |
| | **Base** | 214 | | 132 | | 142 | | 48 | | 47 | | 48 | | 631 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 1-6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Anxiety | 108 | 50% | 63 | 48% | 66 | 46% | 21 | 44% | 26 | 55% | 34 | 71% | 318 | 50% |
| 1 | Insomnia | 44 | 21% | 28 | 21% | 39 | 27% | 16 | 33% | 11 | 23% | 15 | 31% | 153 | 24% |
| 1 | Pain | 70 | 33% | 48 | 36% | 61 | 43% | 18 | 38% | 16 | 34% | 27 | 56% | 240 | 38% |
| 1 | Mobility Issues | 60 | 28% | 44 | 33% | 56 | 39% | 21 | 44% | 17 | 36% | 21 | 44% | 219 | 35% |
| 1 | Fatigue | 113 | 53% | 62 | 47% | 72 | 51% | 29 | 60% | 22 | 47% | 26 | 54% | 324 | 51% |
| 1 | At least one of these has an impact | 167 | 78% | 103 | 78% | 113 | 80% | 40 | 83% | 41 | 87% | 46 | 96% | 510 | 81% |
| 1 | None of the above | 44 | 21% | 29 | 22% | 27 | 19% | 6 | 13% | 6 | 13% | 2 | 4% | 114 | 18% |

## C3. Q3 (excluding A&E visits) by Q15

| | *Q15*<br>*What treatment have you had for your sarcoma?* | Q 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? | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | | Total Excluding A&E | |
| | **Base** | 214 | | 132 | | 142 | | 48 | | 47 | | 48 | | 631 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 1-6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | I have had an operation | 139 | 65% | 86 | 65% | 93 | 65% | 29 | 60% | 26 | 55% | 29 | 60% | 402 | 64% |
| 1 | Radiotherapy | 85 | 40% | 55 | 42% | 47 | 33% | 27 | 56% | 20 | 43% | 12 | 25% | 246 | 39% |
| 1 | Chemotherapy | 72 | 34% | 33 | 25% | 40 | 28% | 19 | 40% | 16 | 34% | 8 | 17% | 188 | 30% |
| 1 | Ablative therapy | 5 | 2% | 3 | 2% | 2 | 1% | 2 | 4% | 1 | 2% | 1 | 2% | 14 | 2% |
| 1 | Something else | 31 | 14% | 10 | 8% | 18 | 13% | 2 | 4% | 3 | 6% | 4 | 8% | 68 | 11% |

## C3. Q3 (excluding A&E visits) by Q31

| | ***Q31*** ***To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing? (Excluding those who went to A&E)*** | **Q3 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?** | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | | Total Excluding A&E | |
| | **Base** | 214 | | 132 | | 142 | | 48 | | 47 | | 48 | | 631 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 1-6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Severely | 44 | 21% | 33 | 25% | 29 | 20% | 9 | 19% | 15 | 32% | 12 | 25% | 142 | 23% |
| 2 | To some extent | 86 | 40% | 49 | 37% | 70 | 49% | 23 | 48% | 14 | 30% | 25 | 52% | 267 | 42% |
| 3 | Slightly | 39 | 18% | 31 | 23% | 23 | 16% | 11 | 23% | 12 | 26% | 4 | 8% | 120 | 19% |
| 1-3 | Had some negative effect | 169 | 79% | 113 | 86% | 122 | 86% | 43 | 90% | 41 | 87% | 41 | 85% | 529 | 84% |
| 4 | Not at all | 18 | 8% | 17 | 13% | 14 | 10% | 4 | 8% | 3 | 6% | 2 | 4% | 58 | 9% |

## C3. Q3 (excluding A&E visits) by Q37

| | | Q3 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? | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Q37 When your treatment finished, what affected you the most day to day? (Excluding those who went to A&E)* | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | | Total Excluding A&E | |
| | **Base** | 214 | | 132 | | 142 | | 48 | | 47 | | 48 | | 631 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 1-6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Coping with side effects of treatment | 27 | 13% | 20 | 15% | 12 | 8% | 8 | 17% | 3 | 6% | 6 | 13% | 76 | 12% |
| 2 | Coping with disability caused by surgery | 16 | 7% | 14 | 11% | 20 | 14% | 8 | 17% | 5 | 11% | 2 | 4% | 65 | 10% |
| 3 | Coping with reduced mobility | 17 | 8% | 17 | 13% | 29 | 20% | 4 | 8% | 6 | 13% | 9 | 19% | 82 | 13% |
| 4 | Loss of sexual function | 2 | 1% | 1 | 1% | 2 | 1% | 2 | 4% | 1 | 2% | 0 | 0% | 8 | 1% |
| 5 | Concerns about money | 4 | 2% | 3 | 2% | 3 | 2% | 3 | 6% | 4 | 9% | 3 | 6% | 20 | 3% |
| 6 | Not getting the support services I needed | 7 | 3% | 5 | 4% | 1 | 1% | 0 | 0% | 0 | 0% | 2 | 4% | 15 | 2% |
| 7 | Worries about infertility / early menopause | 5 | 2% | 5 | 4% | 3 | 2% | 2 | 4% | 0 | 0% | 4 | 8% | 19 | 3% |
| 8 | Something else | 22 | 10% | 11 | 8% | 12 | 8% | 4 | 8% | 4 | 9% | 4 | 8% | 57 | 9% |
| 1-8 | **One of these affected me most** | **100** | **47%** | **76** | **58%** | **82** | **58%** | **31** | **65%** | **23** | **49%** | **30** | **63%** | 342 | **54%** |
| 9 | None of the above | 38 | 18% | 16 | 12% | 22 | 15% | 3 | 6% | 6 | 13% | 7 | 15% | 92 | 15% |

## C4. Q7 by Q15

| | ***Q15 What treatment have you had for your sarcoma?*** | **Q7 Before you were referred for further tests, how many times did you see a healthcare professional about the symptoms you had?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | None - I went straight to hospital | | I saw a healthcare professional once | | I saw a healthcare professional twice | | I saw a healthcare professional 3 or 4 times | | I saw a healthcare professional 5 or more times | | Saw a healthcare professional | |
| | **Base** | 146 | | 162 | | 110 | | 131 | | 99 | | 502 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 2-5 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | I have had an operation | 95 | 65% | 116 | 72% | 61 | 55% | 82 | 63% | 61 | 62% | 320 | 64% |
| 1 | Radiotherapy | 53 | 36% | 71 | 44% | 43 | 39% | 45 | 34% | 39 | 39% | 198 | 39% |
| 1 | Chemotherapy | 39 | 27% | 43 | 27% | 22 | 20% | 48 | 37% | 40 | 40% | 153 | 30% |
| 1 | Ablative therapy | 3 | 2% | 1 | 1% | 2 | 2% | 7 | 5% | 2 | 2% | 12 | 2% |
| 1 | Something else | 19 | 13% | 14 | 9% | 14 | 13% | 15 | 11% | 9 | 9% | 52 | 10% |

## C4. Q7 by Q31

| | ***Q31*** <br> ***To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing?*** | **Q7 Before you were referred for further tests, how many times did you see a healthcare professional about the symptoms you had?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | None - I went straight to hospital | | I saw a healthcare professional once | | I saw a healthcare professional twice | | I saw a healthcare professional 3 or 4 times | | I saw a healthcare professional 5 or more times | | Saw a healthcare professional | |
| | **Base** | 146 | | 162 | | 110 | | 131 | | 99 | | 648 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 2-5 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Severely | 36 | 25% | 25 | 15% | 20 | 18% | 34 | 26% | 46 | 46% | 125 | 19% |
| 2 | To some extent | 59 | 40% | 72 | 44% | 54 | 49% | 65 | 50% | 39 | 39% | 230 | 35% |
| 3 | Slightly | 38 | 26% | 42 | 26% | 24 | 22% | 21 | 16% | 7 | 7% | 94 | 15% |
| 1-3 | **Had some negative effect** | 133 | 91% | 139 | 86% | 98 | 89% | 120 | 92% | 92 | 93% | 449 | 69% |
| 4 | Not at all | 13 | 9% | 22 | 14% | 12 | 11% | 10 | 8% | 6 | 6% | 50 | 8% |

## C4. Q7 by Q37

| | *Q37*<br>*When your treatment finished, what affected you the most day to day?* | Q7 Before you were referred for further tests, how many times did you see a healthcare professional about the symptoms you had? | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | None - I went straight to hospital | | I saw a healthcare professional once | | I saw a healthcare professional twice | | I saw a healthcare professional 3 or 4 times | | I saw a healthcare professional 5 or more times | | Saw a healthcare professional | |
| | **Base** | 146 | | 162 | | 110 | | 131 | | 99 | | 648 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 2-5 | |
| | **Response Options** | n | % | n | % | n | % | n | % | n | % | n | % |
| 1 | Coping with side effects of treatment | 17 | 12% | 22 | 14% | 18 | 16% | 17 | 13% | 13 | 13% | 70 | 11% |
| 2 | Coping with disability caused by surgery | 14 | 10% | 20 | 12% | 10 | 9% | 14 | 11% | 13 | 13% | 57 | 9% |
| 3 | Coping with reduced mobility | 18 | 12% | 21 | 13% | 19 | 17% | 16 | 12% | 17 | 17% | 73 | 11% |
| 4 | Loss of sexual function | 1 | 1% | 2 | 1% | 0 | 0% | 3 | 2% | 1 | 1% | 6 | 1% |
| 5 | Concerns about money | 6 | 4% | 5 | 3% | 6 | 5% | 4 | 3% | 4 | 4% | 19 | 3% |
| 6 | Not getting the support services I needed | 6 | 4% | 2 | 1% | 3 | 3% | 3 | 2% | 4 | 4% | 12 | 2% |
| 7 | Worries about infertility / early menopause | 3 | 2% | 4 | 2% | 4 | 4% | 3 | 2% | 5 | 5% | 16 | 2% |
| 8 | Something else | 13 | 9% | 16 | 10% | 12 | 11% | 11 | 8% | 9 | 9% | 48 | 7% |
| 1-8 | One of these affected me most | 78 | 53% | 92 | 57% | 72 | 65% | 71 | 54% | 66 | 67% | 301 | 46% |
| 9 | None of the above | 22 | 15% | 30 | 19% | 19 | 17% | 19 | 15% | 8 | 8% | 76 | 12% |

## C5. Q11 by Q15

| | *Q15 What treatment have you had for your sarcoma?* | Q11 How long after you first visited your GP / A&E did you receive an accurate diagnosis? | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | |
| | **Base** | 54 | | 94 | | 194 | | 114 | | 86 | | 113 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | I have had an operation | 36 | 67% | 71 | 76% | 118 | 61% | 74 | 65% | 50 | 58% | 69 | 61% |
| 1 | I have had more than one operation | 13 | 24% | 22 | 23% | 67 | 35% | 36 | 32% | 34 | 40% | 45 | 40% |
| 1 | Radiotherapy | 16 | 30% | 41 | 44% | 73 | 38% | 45 | 39% | 38 | 44% | 39 | 35% |
| 1 | Chemotherapy | 19 | 35% | 28 | 30% | 48 | 25% | 36 | 32% | 35 | 41% | 26 | 23% |
| 1 | Ablative therapy | 2 | 4% | 1 | 1% | 5 | 3% | 3 | 3% | 3 | 3% | 1 | 1% |
| 1 | Something else | 5 | 9% | 8 | 9% | 25 | 13% | 16 | 14% | 9 | 10% | 9 | 8% |

## C5. Q11 by Q31

| | ***Q31*** ***To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing?*** | **Q11 How long after you first visited your GP / A&E did you receive an accurate diagnosis?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | |
| | **Base** | 54 | | 94 | | 194 | | 114 | | 86 | | 113 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Severely | 17 | 31% | 24 | 26% | 36 | 19% | 24 | 21% | 27 | 31% | 37 | 33% |
| 2 | To some extent | 13 | 24% | 32 | 34% | 94 | 48% | 58 | 51% | 39 | 45% | 59 | 52% |
| 3 | Slightly | 19 | 35% | 27 | 29% | 44 | 23% | 21 | 18% | 14 | 16% | 8 | 7% |
| 1-3 | Had some negative effect | 49 | 91% | 83 | 88% | 174 | 90% | 103 | 90% | 80 | 93% | 104 | 92% |
| 4 | Not at all | 5 | 9% | 11 | 12% | 20 | 10% | 11 | 10% | 5 | 6% | 8 | 7% |

## C5. Q11 by Q37

| | ***Q37***<br>***When your treatment finished, what affected you the most day to day?*** | **Q11 How long after you first visited your GP / A&E did you receive an accurate diagnosis?** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Less than 2 weeks | | More than 2 weeks but less than 4 weeks | | More than 4 weeks but less than 3 months | | More than 3 months but less than 6 months | | More than 6 months but less than a year | | More than a year | |
| | **Base** | 54 | | 94 | | 194 | | 114 | | 86 | | 113 | |
| | **Response Code** | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Coping with side effects of treatment | 5 | 9% | 8 | 9% | 30 | 15% | 15 | 13% | 12 | 14% | 17 | 15% |
| 2 | Coping with disability caused by surgery | 4 | 7% | 12 | 13% | 22 | 11% | 11 | 10% | 11 | 13% | 12 | 11% |
| 3 | Coping with reduced mobility | 8 | 15% | 11 | 12% | 27 | 14% | 15 | 13% | 13 | 15% | 18 | 16% |
| 4 | Loss of sexual function | 0 | 0% | 1 | 1% | 1 | 1% | 3 | 3% | 3 | 3% | 1 | 1% |
| 5 | Concerns about money | 1 | 2% | 3 | 3% | 6 | 3% | 3 | 3% | 6 | 7% | 6 | 5% |
| 6 | Not getting the support services I needed | 3 | 6% | 5 | 5% | 1 | 1% | 4 | 4% | 1 | 1% | 5 | 4% |
| 7 | Worries about infertility / early menopause | 0 | 0% | 3 | 3% | 4 | 2% | 6 | 5% | 3 | 3% | 3 | 3% |
| 8 | Something else | 6 | 11% | 7 | 7% | 20 | 10% | 9 | 8% | 9 | 10% | 8 | 7% |
| 1-8 | One of these affected me the most | 27 | 50% | 50 | 53% | 111 | 57% | 66 | 58% | 58 | 67% | 70 | 62% |
| 9 | None of the above | 12 | 22% | 17 | 18% | 33 | 17% | 15 | 13% | 7 | 8% | 16 | 14% |

## C6. Q24 by Q15

| | *Q15*<br>*What treatment have you had for your sarcoma?* | Q24 Were you treated by a specialist sarcoma cancer team? | | | |
|---|---|---|---|---|---|
| | | Yes | | No | |
| | **Base** | 527 | | 87 | |
| | **Response Code** | 1 | | 2 | |
| | **Response Options** | **n** | **%** | **n** | **%** |
| 1 | I have had an operation | 340 | 65% | 57 | 66% |
| 1 | I have had more than one operation | 178 | 34% | 26 | 30% |
| 1 | Radiotherapy | 225 | 43% | 15 | 17% |
| 1 | Chemotherapy | 166 | 31% | 16 | 18% |
| 1 | Ablative therapy | 14 | 3% | 1 | 1% |
| 1 | Something else | 57 | 11% | 8 | 9% |

## C7. Q25 by Q15

| | ***Q15*** <br> ***What treatment have you had for your sarcoma?*** | **Q25 Were you given a written care plan that told you all the information you needed about your sarcoma treatment from start to finish?** | | | | | |
|---|---|---|---|---|---|---|---|
| | | Yes, a plan that told me everything | | Yes, but it only told me some things | | No, I was not given a plan | |
| | **Base** | 144 | | 96 | | 356 | |
| | **Response Code** | 1 | | 2 | | 3 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | I have had an operation | 109 | 76% | 56 | 58% | 215 | 60% |
| 1 | I have had more than one operation | 34 | 24% | 30 | 31% | 127 | 36% |
| 1 | Radiotherapy | 76 | 53% | 38 | 40% | 105 | 29% |
| 1 | Chemotherapy | 46 | 32% | 33 | 34% | 86 | 24% |
| 1 | Ablative therapy | 0 | 0% | 2 | 2% | 13 | 4% |
| 1 | Something else | 14 | 10% | 12 | 13% | 39 | 11% |

## C7. Q25 by Q31

| | ***Q31*** <br> ***To what extent has your diagnosis and treatment of sarcoma negatively affected your overall mental health / emotional wellbeing?*** | **Q25 Were you given a written care plan that told you all the information you needed about your sarcoma treatment from start to finish?** | | | | | |
|---|---|---|---|---|---|---|---|
| | | Yes, a plan that told me everything | | Yes, but it only told me some things | | No, I was not given a plan | |
| | **Base** | 144 | | 96 | | 356 | |
| | **Response Code** | 1 | | 2 | | 3 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Severely | 29 | 20% | 27 | 28% | 96 | 27% |
| 2 | To some extent | 53 | 37% | 49 | 51% | 163 | 46% |
| 3 | Slightly | 40 | 28% | 14 | 15% | 67 | 19% |
| 3 | Had some negative effect | 122 | 85% | 90 | 94% | 326 | 92% |
| 4 | Not at all | 22 | 15% | 6 | 6% | 29 | 8% |

## C7. Q25 by Q37

| | ***Q37*** ***When your treatment finished, what affected you the most day to day?*** | **Q25 Were you given a written care plan that told you all the information you needed about your sarcoma treatment from start to finish?** | | | | | |
|---|---|---|---|---|---|---|---|
| | | Yes, a plan that told me everything | | Yes, but it only told me some things | | No, I was not given a plan | |
| | **Base** | 144 | | 96 | | 356 | |
| | **Response Code** | 1 | | 2 | | 3 | |
| | **Response Options** | **n** | **%** | **n** | **%** | **n** | **%** |
| 1 | Coping with side effects of treatment | 21 | 15% | 20 | 21% | 38 | 11% |
| 2 | Coping with disability caused by surgery | 16 | 11% | 11 | 11% | 38 | 11% |
| 3 | Coping with reduced mobility | 24 | 17% | 13 | 14% | 42 | 12% |
| 4 | Loss of sexual function | 1 | 1% | 1 | 1% | 7 | 2% |
| 5 | Concerns about money | 7 | 5% | 5 | 5% | 13 | 4% |
| 6 | Not getting the support services I needed | 3 | 2% | 1 | 1% | 12 | 3% |
| 7 | Worries about infertility / early menopause | 4 | 3% | 2 | 2% | 10 | 3% |
| 8 | Something else | 10 | 7% | 4 | 4% | 43 | 12% |
| 1-8 | One of these affected me most | 86 | 60% | 57 | 59% | 203 | 57% |
| 9 | None of the above | 26 | 18% | 12 | 13% | 55 | 15% |

## 7.2. Appendix B – Free text coding summary counts

### B1. Symptoms

| Symptoms | Adult | Parents | F&C |
|---|---|---|---|
| | 02f_Other | 02f_Other | 03f_Other |
| Misc pain / discomfort / irritation | 48 | 5 | 23 |
| Bleeding (including in stools and urine) / blood related | 42 | 2 | 14 |
| Bone related / pain, Restricted movement in joints, numbness | 27 | 4 | 25 |
| Tummy (abdominal) discomfort / pain | 22 | 2 | 22 |
| A mass, growth or welling (inc painless lump in the abdomen) | 29 | 1 | 13 |
| Fatigue (tiredness or feeling of weakness), sleep issues | 19 | 2 | 8 |
| Bowel / urinary related | 11 | 4 | 1 |
| Being sick (vomiting) / nausea | 7 | 1 | 6 |
| Cough | 6 | 0 | 8 |
| High temperature (fever) / sweating at night | 10 | 0 | 4 |
| Breathlessness | 7 | 2 | 3 |
| Anaemia (low level of red blood cells) | 9 | 0 | 0 |
| Weight change | 6 | 1 | 2 |
| Eyes, Ears, Nose, Mouth, Throat | 5 | 1 | 1 |
| Heart related | 3 | 1 | 1 |
| Dizziness / balance issues | 2 | 0 | 0 |
| Hair loss | 1 | 0 | 0 |
| Spasms | 1 | 0 | 0 |
| Ulcers | 1 | 0 | 0 |
| Too broad to categorise | 7 | 1 | 6 |

## B2. Side effects

| Side Effects | Adult | Parents |
|---|---|---|
| | 22r_Other | 23q_Other |
| Movement issues / bone or joint issues | 12 | 1 |
| Eyes, ears, nose, mouth, throat | 9 | 3 |
| Bowel / bladder issues, ulcers, reflux, gastric issues | 11 | 0 |
| Misc pain / discomfort | 8 | 1 |
| Mental health | 4 | 3 |
| Fatigue, loss of strength, dizziness, sleep related | 6 | 0 |
| Infertility, menopause, hormonal | 4 | 0 |
| Additional medical issue (e.g. surgery, seizure etc.) | 3 | 0 |
| Infection related | 3 | 0 |
| Seeping / bleeding | 3 | 0 |
| Cramping | 1 | 1 |
| Swelling related | 2 | 0 |
| Weight change | 2 | 0 |
| Heart issues | 0 | 1 |
| Hernia | 1 | 0 |
| Vitamin deficiency | 1 | 0 |
| Too broad to categorise | 2 | 1 |

## B3. Main side effect

| Main Side Effect | Adult | Parents | F&C |
|---|---|---|---|
| | 23r_Other | 24q_Other | 10r_Other |
| Movement issues / bone or joint related | 12 | 1 | 19 |
| Mental health | 5 | 3 | 12 |
| Eyes, ears, nose, mouth, throat | 5 | 2 | 1 |
| Fatigue, loss of strength, dizziness, sleep related | 2 | 0 | 6 |
| Seeping / bleeding | 3 | 0 | 3 |
| Weight change | 3 | 0 | 3 |
| Infertility, menopause, hormonal | 4 | 0 | 1 |
| Misc pain / discomfort | 1 | 1 | 3 |
| Bowel / bladder issues, ulcers, reflux, gastric issues | 2 | 0 | 2 |
| Additional medical issue (e.g. surgery, seizure etc.) | 1 | 0 | 2 |
| Infection related | 1 | 1 | 1 |
| Breathlessness | 0 | 0 | 2 |
| Hernia | 1 | 0 | 0 |
| Cramping | 0 | 0 | 0 |
| Swelling related | 0 | 0 | 0 |
| Vitamin deficiency | 0 | 0 | 0 |
| Too broad to categorise | 0 | 0 | 6 |

## B4. Sarcoma location

| Sarcoma Location | Adult | Parents | F&C |
|---|---|---|---|
| | 46c | 46c | 24c |
| Abdomen | 68 | 2 | 43 |
| Ankle | 5 | 0 | 5 |
| Arm (lower) | 10 | 0 | 7 |
| Arm (Upper) | 9 | 1 | 6 |
| Arm (Other/Unspecified) | 8 | 1 | 11 |
| Back | 6 | 2 | 11 |
| Bladder/bowel/Intestine | 25 | 3 | 10 |
| Bone | 2 | 0 | 6 |
| Brain | 4 | 0 | 10 |
| Breast | 21 | 0 | 7 |
| Buttocks | 10 | 0 | 9 |
| Chest | 22 | 1 | 12 |
| Foot | 19 | 4 | 8 |
| Groin | 15 | 0 | 6 |
| Hand | 7 | 1 | 6 |
| Head | 25 | 16 | 15 |
| Heart | 1 | 1 | 11 |
| Hip | 8 | 1 | 8 |
| Kidney | 9 | 0 | 6 |
| Leg (Upper) | 118 | 3 | 58 |
| Leg (Lower) | 45 | 4 | 13 |
| Leg (Knee) | 24 | 0 | 17 |
| Leg (Other/unspecified) | 15 | 1 | 21 |
| Liver | 27 | 1 | 19 |
| Lungs | 51 | 3 | 58 |
| Neck | 11 | 5 | 13 |
| Pelvis | 31 | 2 | 22 |
| Ribs | 11 | 2 | 6 |
| Shoulder | 17 | 1 | 12 |
| Spine | 20 | 5 | 26 |
| Stomach | 41 | 0 | 16 |
| Testes | 2 | 4 | 3 |
| Uterus | 47 | 0 | 18 |
| Other | 50 | 7 | 46 |

## B5. Sarcoma subtype

| Sarcoma Subtype | Adult | Parents | F&C |
|---|---|---|---|
| | 46b | 46b | 24b |
| Rhabdomyosarcoma | 33 | 27 | 26 |
| Spindle cell sarcoma | 17 | 0 | 12 |
| Angiosarcoma | 91 | 0 | 42 |
| n/a | 23 | 0 | 23 |
| Osteosarcoma | 63 | 6 | 42 |
| Chondrosarcoma | 38 | 1 | 18 |
| Chordoma | 1 | 0 | 0 |
| Liposarcoma | 91 | 0 | 42 |
| Pleomorphic sarcoma | 6 | 0 | 3 |
| Endometrial stromal sarcoma | 33 | 27 | 26 |
| Epithelioid sarcoma | 3 | 1 | 5 |
| Ewing's sarcoma | 24 | 6 | 21 |
| Gastrointestinal stromal tumour (GIST) | 26 | 0 | 3 |
| Synovial sarcoma | 63 | 6 | 42 |
| Kaposi's sarcoma | 2 | 0 | 0 |
| Leiomyosarcoma | 74 | 0 | 40 |
| Wild-type GIST | 10 | 0 | 2 |
| Malignant Peripheral Nerve Sheath Tumour | 8 | 0 | 10 |
| Undifferentiated sarcoma | 7 | 0 | 8 |
| Perivascular epithelioid | 1 | 0 | 2 |
| Other | 66 | 9 | 38 |