The National Sarcoma Survey 2015
Transforming patient experience
About Sarcoma UK

Sarcoma UK is the only charity in the UK focusing on all types of sarcoma.

Our mission is to increase knowledge and awareness of sarcoma through ground-breaking programmes that inspire involvement and transform the landscape for everyone affected by sarcoma.

- We raise sarcoma awareness to initiate change and improve standards of treatment and care
- We seek answers through research
- We provide support & information for the sarcoma community

About sarcoma

Sarcomas are rare cancers that develop in the muscle, bone, nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissues. They can affect almost any part of the body, on the inside or the outside.

Sarcomas commonly affect the arms, legs and trunk. They also appear in the stomach and intestines as well as behind the abdomen (retroperitoneal sarcomas) and the female reproductive system (gynaecological sarcomas).

People can survive sarcoma if their cancer is diagnosed early, when treatments can be effective and before the sarcoma has spread to other parts of the body. It is vital that patients be referred to a specialist sarcoma team as early as possible.

- There are three main types of sarcoma: soft tissue sarcoma, bone sarcoma and gastrointestinal stromal tumours (GIST)
- There are around 100 different sub-types of sarcoma
- 10 people every day are diagnosed with sarcoma in the UK
- About 3,800 new cases of sarcoma are diagnosed each year in the UK which makes up approximately 1% of all cancer diagnoses
- Every year 3,330 people are diagnosed with a soft tissue sarcoma (including GIST)
- 500 people are diagnosed with a bone sarcoma every year
- In general, patients with a bone or soft tissue diagnosis tend to be younger than the majority of cancer patients. 16% of bone or soft tissue sarcomas are diagnosed in patients less than thirty years of age, compared to around 2% of all cancers. 37% of bone or soft tissue sarcoma patients are aged less than 50 years
- Sarcomas make up 15% of all childhood cancers (0-14 years) and 11% of all cancer diagnoses in teenagers and young people (15-24 years)
- In Scotland, 180 new cases of sarcoma are diagnosed each year while in Northern Ireland, 100 new cases of sarcoma are diagnosed each year.
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**Production**

Survey design, fieldwork and analysis: Quality Health Ltd  
**Report authors:** Lindsey Bennister (Sarcoma UK); Dr Reg Race (Quality Health)  
**Design:** INQ Design Ltd 020 7737 5775
Introduction

This National Sarcoma Patient Experience Survey, conducted in 2015, is one of the most comprehensive surveys undertaken into the experiences of people diagnosed with sarcoma in the UK. It provides independent evidence about patients’ experiences, from first concern that something was wrong, through their diagnosis, treatment and follow-up.

In England, sarcoma patients are treated under a model of specialised sarcoma services consisting of specialist sarcoma centres operating a multi-disciplinary approach where all treatment is discussed and confirmed by a team of sarcoma clinical experts. The model in England is supported by national guidelines from the National Institute for Health and Care Excellence (Improving Outcomes for People with Sarcoma 2006) and more recently the National Institute for Health and Care Excellence’s Sarcoma Quality Standard (2015). In addition, consensus guidelines from the British Sarcoma Group and European clinical guidelines are available to further guide the management and care of sarcoma patients. However, in spite of this, sarcoma patients in England report some of the poorest experiences of any cancer type, and their experiences are significantly lower than the experiences of people diagnosed with the most common cancers (National Cancer Patient Experience Survey 2014). In Scotland, the Scottish Sarcoma Managed Clinical Network operates a similar model of care, specialised into five main centres providing coverage throughout Scotland.

Sarcoma UK commissioned and funded this survey to gain a greater understanding of the experiences of sarcoma patients, using the NCPES as a base line. We wanted to understand the key drivers for good patient experience so that we can work with and support specialist sarcoma services to bring about the changes needed to improve patient experience.

Positively, the findings indicate that patients report an enhanced experience once they are within sarcoma specialist services, which provides strong evidence for the rationale for this model of care. The open text responses (where respondents were asked to make suggestions for improvements to sarcoma services) make positive reading, with the majority of respondents taking the opportunity to praise their sarcoma specialists. The suggestions made by patients are
reflected in the recommendations, which are intended to offer solutions and ideas to improve patient experience.

Sarcoma UK’s *Strategy: Transforming the Landscape for Sarcoma 2014-2020* sets out our Goal that ‘Everyone affected by sarcoma will have access to the best treatment and care’ and the following targets:

- The NHS experience of sarcoma patients will have moved from being one of the worst of all cancers, to being amongst the best of the rarer cancers
- 100% of people diagnosed with sarcoma will be treated under the care of a sarcoma multi-disciplinary team (compared to 60% in 2013)

We hope that this report will help improve the experiences of sarcoma patients. It provides the sarcoma community with ideas and opportunities to work collaboratively to design health services that are patient focused and that ultimately will improve outcomes for all patients with sarcoma.

*Lindsey Bennister*  Chief Executive
Executive Summary

The National Sarcoma Survey (2015) is a comprehensive and independent survey of the experiences of bone and soft tissue sarcoma patients in England and Scotland, commissioned and funded by Sarcoma UK.

The survey identifies the key drivers for good sarcoma patient experience, and provides an extensive dataset of the experiences of 650 sarcoma patients with bone and soft tissue sarcoma.

The survey focused on patient experience:
1. To diagnosis
2. During treatment
3. Post-treatment

It was delivered by Quality Health, the providers of the NHS National Cancer Patient Experience Survey. An Expert Panel of patients, carers, health professionals and researchers helped to shape the questions and key recommendations.

England

Response rate
558 respondents (64% response rate)
Soft tissue sarcoma patients: 418
Bone sarcoma patients: 140

Respondent profile
Sarcoma survivors who had responded to the most recent NHS National Patient Experience Surveys (2012-2014), having previously been in active treatment.

1. To diagnosis

Signs & symptoms
- The most common presenting symptoms were:
  - painless lump (41%)
  - something else (not defined 31%)
  - lump increasing in size (30%).
- 31% of bone sarcoma patients presented with bone pain.
Executive Summary

Delays in presentation
- 18% of patients presented to a medical practitioner more than 6 months after first noticing symptoms (24% bone sarcoma, 16% soft tissue sarcoma).
- 17% of patients with bone sarcoma waited more than 12 months before presenting to a medical practitioner.

Inappropriate treatment
- One third of patients who presented to their GP with sarcoma symptoms were not treated appropriately.
- 9% were treated for something else.
- 18% were told their symptoms were not serious, with only 9% of these advised to come back if symptoms persisted.
- There was a notable difference in misdiagnosis in younger patients presenting to their GP.
- 48% of the youngest age group (16-34) were treated for another condition or told their symptoms were not serious, compared with 23% of patients aged 85+.
- 25% of patients who presented at A&E with symptoms were not referred for diagnostic tests or specialist investigation.

2. During treatment

Specialist sarcoma teams
- 87% of patients were treated by a specialist sarcoma team.
- 77% of patients has access to a clinical nurse specialist (CNS).

Complex pathways
- 66% of patients attended more than one hospital for treatment.
- 50% of patients travelled more than 20 miles for treatment (surgery).
- 90% of patients did not mind travelling for treatment (surgery).

Informed decision-making
- 87% of respondents felt well informed to make decisions about their treatment and care.
Clinical trials
- 67% of patients were not asked about taking part in a clinical trial.
- Of those who were asked, only 22% took up the opportunity.
- Younger patients (16-34) were more likely to be asked about taking part in trials.

Side effects from treatment
- Pain, fatigue, dry/painful mouth, and loss of nerve sensation were the treatment-related side effects that had the greatest impact on daily life.

Emotional support
- One third of patients felt that emotional support from the hospital was inadequate.
- Only 28% of patients were told about national sarcoma charities and the support and information they provide.
- Only 21% of patients were given information about local sarcoma support groups.

3. Post-treatment

Rehabilitation
- The most common rehabilitation services that sarcoma patients were referred to were: physiotherapy, occupational therapy, dietetics, prosthetics and wheelchair services.
- Referral to rehabilitation services was much more frequent for bone sarcoma patients than soft tissue sarcoma patients.
- Younger people are more likely to be referred to rehabilitation services than older people.
- Almost half of patients did not have a positive experience of rehabilitation.

Follow up
- 87% of patients felt their follow-up pathway was clear and 90% knew who to contact at the hospital for help and information.

Post-treatment concerns
- 71% of patients were worried about their sarcoma coming back.
- 49% of bone sarcoma patients were concerned about disability caused by surgery.
- Post-treatment concerns were more pronounced in the youngest age group.
Executive Summary

Scotland

Questionnaires were distributed via the Scottish Sarcoma Network to patients in sarcoma clinics throughout Scotland.

Number of respondents
92

Respondent profile
Sarcoma patients attending hospital for treatment.

Analysis of data collected for Scotland had many similarities with the England results. The main differences were:

- Patients were more likely to receive all their treatment in one hospital, with only 11% attending more than one hospital for treatment.
- Patients were more likely to have the same CNS in charge from start to finish of treatment.
- 85% of sarcoma patients were not asked about taking part in clinical trials. Of those who were asked, only 10% took up the opportunity.

Key drivers of good sarcoma patient experience

1. Early suspicion of sarcoma
   By GPs, A&E staff and patients.
2. Streamlined routes into sarcoma specialist services
   To avoid inappropriate treatment.
3. Clear navigation within sarcoma specialist services
   A personalised written treatment plan that sets out who is responsible for treatment and where it is being delivered.
4. Information about clinical trials
   Easy-to-access, comprehensive information for clinicians and patients.
5. Access to emotional support
   Signpost to national and local sarcoma support services eg Sarcoma UK Support Line.
6. Access to specialist sarcoma rehabilitation services
   Offer sarcoma patients the opportunity for specialist rehabilitation assessment irrespective of age or type of sarcoma.
Methodology

This National Sarcoma Survey in England and Scotland was commissioned and funded by Sarcoma UK, the bone and soft tissue cancer charity, and delivered by Quality Health.

The methodology used for the survey in each jurisdiction was different. In England, questionnaires were posted to patients by Quality Health, with two reminders sent by post to non-respondents as required. In Scotland, questionnaires were despatched to participating hospitals and handed out to patients in clinic by NHS staff. Identical questionnaires were used in England and Scotland. The questionnaire was developed by Quality Health in conjunction with Sarcoma UK, with input from an Expert Panel of patients and clinicians, and tested independently before use.

In England, the sample was drawn from respondents to the National Cancer Patient Experience Surveys (NCPES) 2010-14 who had indicated that they were happy to be contacted further about their cancer and health status. A sample of 900 was taken from this respondent group, with preference given to those respondents from the 2014, 2013 and 2012 NCPES sarcoma respondent groups. Deceased checks were undertaken through DBS (demographic batch service) to identify those patients who had died since completing the initial NCPES questionnaire.

It is important to recognise that the survey in England is therefore a survey of sarcoma patients who have survived for a period of time, after being in active treatment previously. The survey in Scotland is a survey of sarcoma patients at a different point, namely that of attending hospital for treatment. Survival is linked to the stage at which the cancer is diagnosed, and this is in turn linked to age, deprivation scores, and ethnicity. Other factors such as presentation through an emergency route are also significant. This means that survivors are likely to be different in background from those patients who have died.

Fieldwork was undertaken in England in the period January-March 2015, and in Scotland between March and May 2015.

The differences in methodology required in England and Scotland is worthy of note. Scotland as yet has no database of patient respondents who have agreed to further questionnaires being sent to them. In England, the sample chosen for the National Sarcoma Survey is robust because most patients who respond to the NCPES also agree to a further questionnaire being sent to them, with approximately 80% agreeing to this process. In Scotland, however, self-selection of the sample is probably more pronounced because it is not possible to know how many patients were in clinic in the relevant time periods being treated for a sarcoma; how many refused to participate.
having been asked by staff if they would do so; and how many patients were not asked by staff to participate at all. Because the questionnaires in Scotland were not associated with the collection of personal data (name, address) it was not possible to send reminders to non-respondents which explains the response rate differential between Scotland and England. In addition, and because the Scotland questionnaire was identical to that in England, no demographic data was collected from Scottish respondents. There is therefore no information on gender, age ranges, or long term conditions. In conclusion, it is clear that some caution must be exercised when assessing differences between the England and Scotland data, which may have been affected by response rate factors and self-selection issues.

The response rate in England was a very positive 64% (558 respondents), with almost identical response rates by year of participation in NCPES (64% from the 2014 CPES cohort; 65% from 2013; and 62% from 2012). There were 92 responses from Scotland but it is not possible to calculate a response rate.

We have undertaken multiple regression tree analysis on the response data from England and Scotland in order to identify which variables were most strongly associated with high scores given by patients in this National Sarcoma Survey 2015, which informs the recommendations.

**Opportunities for future work**

The survey did not seek the experiences and opinions of the professionals involved in the treatment and care of sarcoma patients (however, they were represented on the Expert Panel who developed the recommendations in this report). There is potential for a follow-up survey of sarcoma specialist health professionals, to understand more about their challenges and perspectives in order to provide an enhanced picture.

**Expert Panel**

Following analysis of the survey data by Quality Health, Sarcoma UK convened an Expert Panel to consider the findings and help shape the focus and recommendations for this report. The list of members of the Panel is in Appendix B (page 35). We would like to thank them for their valuable input to this report.
1. Diagnosis

Delayed diagnosis is a major issue for patients and it is widely acknowledged in published papers that routes to diagnosis for sarcoma patients need to be quicker and more streamlined.

We wanted to find out about patients' experiences of diagnosis: from their initial signs and symptoms, how long it took them to decide to see their doctor, and the actions that the first doctor took to investigate their symptoms.

Signs and symptoms

The most common health problems and symptoms identified by patients which made them think that something was wrong were:

- Painless lump (41%)
- Something else (31%)
- Lump increasing in size (30%)

However, there were very different symptoms identified by bone and soft tissue sarcoma patients. The most common symptoms identified by bone sarcoma patients were bone pain (31%) and painless lump (28%), whereas with soft tissue patients the...
The most common symptoms were painless lump (45%), lump increasing in size (33%) and something else (33%).

The youngest group of patients noticed different kinds of health problems than did those who were older. Younger patients were less likely to identify painless lumps than were the oldest patients, but younger patients were the most likely to identify painful lumps. The oldest age group were most likely to identify lumps increasing in size.

Men were more likely to say that they had painless or painful lumps, or lumps increasing in size, than were women; women were much more likely to say they had “something else” as a symptom than were men. This requires further investigation.

**Delays in presentation**

These results highlight a significant delay by sarcoma patients themselves in seeking medical advice about symptoms. The survey asked about the length of time between first noticing symptoms and first seeing a GP or going to A&E. 18% of all sarcoma patients presented more than 6 months from noticing the first symptoms. However, 24% of bone...
sarcoma patients presented at 6 months or later (including 17% who waited more than a year), whereas 16% of soft tissue sarcoma patients presented at 6 months or later.

**Inappropriate referral and investigations**

Although many patients were referred by the GP for tests (34%), or to a hospital specialist (33%), there were some patients who clearly did not receive appropriate referrals. 27% of all respondents said they were started on treatment for another condition or were told the symptoms were not serious and to come back/not come back if they persisted. 9% were told the symptoms were not serious and were not told to come back if the symptoms persisted, and a further 9% were told the symptoms were not serious but were told to come back if they persisted.

Of the small number of patients who attended A&E rather than their GP, similar issues arose. 25% of this group were started on treatment for another condition, or were told the symptoms were not serious and to come back/not come back if they persisted.

There is evidence of misdiagnosis on a more substantial scale by GPs when young patients present. 48% of the 16-34 age group said that the GP started treating them for another condition, or told them that the symptoms were not serious, compared to 23% of the 85+ age group.

If women attended hospital A&E for assessment, they were much more likely to be started on treatment for another condition, or told that the symptoms were not serious, than were men (33% of women compared to 17% of men).

It is extremely worrying that so many patients were started on treatment for something other than sarcoma, which we assume includes surgical procedures carried out by non-sarcoma surgical teams. It highlights the low level of suspicion, education and knowledge about sarcoma in health professionals in both primary and secondary care.

Very few patients were told by the GP or A&E doctor that they might have a sarcoma: only 1 in 5 (20% overall) said that they were told this.

In Scotland, patients were much less likely to be told that they may have a sarcoma. Only 9% of patients were told that by the GP or A&E doctor that they might have a sarcoma, compared to 20% in England.
2. Treatment

The previous section on diagnosis highlights the worryingly large number of patients who are started on treatment for something else. More positively, this section highlights that the majority of respondents were treated by sarcoma specialist teams, and that patients are prepared to travel to access the best treatment and care available at sarcoma specialist centres.

However, there is much that still can be done to help patients better understand how their care is managed and delivered, and who is responsible for it.

Specialist sarcoma teams

Reassuringly, almost 90% of patients said they were definitely treated by a sarcoma specialist team, despite the previous section highlighting that a significant number of patients having been started on treatment for something else, implying a delay in reaching sarcoma specialists. A small number of patients said they were not treated by a specialist sarcoma team (3% overall) and a further 10% were not sure whether they were or not.

“I want assurance that a multi-disciplinary team is involved in my case... I need to be sure appropriate specialists are reviewing my case.”

Clinical nurse specialists (CNS)

“A nurse to contact if I was worried about anything.”

90% of patients said that they had access to a sarcoma clinical nurse specialist. For 37% of patients who had a CNS in charge of their care, it was the same
person in charge from start to finish; 27% said they always had a CNS but that it was a different person at different times; 13% said that sometimes they had a CNS and sometimes they did not. 10% said they did not have a CNS in charge at any time at all, and this may reflect the patients who were not treated by a specialist sarcoma team (or unsure whether they were).

80% of sarcoma patients in Scotland were treated by a specialist sarcoma team. Sarcoma patients in Scotland were more likely to have the same CNS in charge from start to finish.

**Complex pathways**

Most patients attended more than one hospital for their treatment. This is not unusual given that sarcoma is a rare cancer which is treated mainly in tertiary centres, with some patients attending other units for radiotherapy and chemotherapy. Only 1 in 3 patients overall (34%) attended one hospital for treatment. 45% attended 2 hospitals, and 21% attended three or more.

For patients who also had radiotherapy or chemotherapy in addition to an operation, most attended a different hospital for this treatment than the one at which they had had their operation.

“One improvement could have been better exchange of information/progress updates between the hospital where I had surgery and the one where I had chemotherapy. It was all very smooth and coordinated over the 2 weeks to diagnosis and treatment, but once I had started treatment, it was less so.”

Half of sarcoma patients had to travel more than 20 miles for treatment (operation, radiotherapy or chemotherapy), however 90% of patients said they did not mind travelling. This is congruent with findings from other patient surveys in which this question has featured. It is consistently the view of patients that they are
prepared to travel significant distances if it means they get treated effectively. However, some responses in the open text section did question why radiotherapy and chemotherapy treatments were not delivered locally under the direction of the sarcoma multi-disciplinary team.

Patients in Scotland were more likely to receive all their treatment at the same hospital. Only 11% of patients in Scotland went to more than one hospital for treatment, compared to 38% of patients in England.

**Information to assist decision-making/written treatment plans**

Most patients (87% overall) said they were given enough information to help them make decisions about their care and treatment. This is very positive and indicates that patients feel informed at a crucial time in their treatment.

The key drivers analysis undertaken on responses to this survey indicates that having a written treatment plan is the most important determinant of high scores given by patients throughout the survey. However, about 4 in 10 patients (39% overall) said they did not receive a written treatment plan at all. Only 48% overall said they received a plan that told them everything from start to finish. A slightly higher proportion of bone sarcoma patients said they were given a treatment plan that told them everything.

Sarcoma patients in Scotland were less likely to be given a written treatment plan that told them everything from start to finish. Only 34% of patients were given a written plan.

“I would have liked clearer communication about my treatment plan, and once treatment has finished, clear information about follow up.”
Key Findings

Side effects from treatment

Side effects of treatment can be an important contributing factor to overall patient experience. In the questionnaire, we listed 15 side effects believed to be the most common amongst sarcoma patients, and asked patients to say which of them had the most impact on their life. Four were identified as having the most perceived impact on daily life:

- pain (especially for bone sarcoma patients)
- daytime fatigue (especially for soft tissue sarcoma patients)
- soreness/dryness in the mouth (especially for bone sarcoma patients)
- loss of nerve sensation/feeling (equally for bone and soft tissue sarcoma patients)

On every item identified in the questionnaire as a potential side effect bar one, bone sarcoma patients were more likely to say they had experienced them than soft tissue sarcoma patients. For bone sarcoma patients, 55% had experienced pain, 49% soreness/dryness in the mouth, 48% daytime fatigue, 46% changes to skin, nails and hair, and 45% loss of nerve sensation or feeling.

The incidence of specific side effects was markedly higher amongst the younger age groups than was the case with older patients and the perceived side-effects of treatment for sarcoma seem to decline with age. On almost all items, older patients reported fewer side effects than did the youngest age group. On almost all items, older patients report a lesser impact on their life than do the youngest patients. However, more older patients than younger ones felt that daytime fatigue and difficulty getting to sleep were impacting on their lives.

The most common side effects of treatment for soft tissue sarcoma patients were daytime fatigue (48%), changes to skin nails or hair (42%), pain (41%), and loss of nerve sensations/feeling (37%). The only side effect experienced more frequently by soft tissue sarcoma patients was lymphoedema.

In terms of the side effects that have had most impact on the patient’s life, pain was most frequently mentioned by bone patients (36%). Soft tissue patients mentioned pain (23%) and daytime fatigue (19%) as the most impactful symptoms.
Side effects of treatment were noticed by women in more substantial numbers than by men. This was particularly significant in respect of nausea/vomiting; constipation; changes to skin, nails and hair; soreness/dryness in the mouth; loss of nerve sensations/feeling; loss of appetite; and 5 other named side effects.

**Emotional support and information**

There have been big improvements in the support and information available to sarcoma patients, nationally and locally. However, there were many patients who said that they were not given sufficient emotional support in particular by hospital staff. 8% said they were not given any support and would have liked more and a further 28% said they were given some but would have liked more. Therefore, over a third of patients felt they needed more emotional support.

More patients were given information about local cancer support groups covering all cancers than were given information about local sarcoma support groups. 41% of all patients were given information about generic local groups whilst only 21% were given information about local support groups covering sarcoma. Soft tissue sarcoma patients were a little more likely to receive this information than were bone sarcoma patients.

Only 28% of patients were made aware of the support and information provided by
Key Findings

a national sarcoma charity such as Sarcoma UK (for example, their range of patient information booklets and the Sarcoma Toolkit for newly diagnosed patients, and support services).

Patients were asked whether they had used any of the national cancer charity websites to get information about cancer. Of the websites mentioned specifically, the top three consulted were Macmillan Cancer Support, Cancer Research UK, and Sarcoma UK.

Website usage was strongly related to age. 34% of all respondents had used the Sarcoma UK website in the 35-44 age group, but this declined steeply to 5% in the 85+ age group.

Younger patients were less likely to say that they received enough emotional support from hospital staff than were older patients.

The use of websites to gain information about their sarcoma was far more pronounced amongst the youngest age group.

Men were less likely to say that they needed emotional support from staff, and women were less likely to say that they received enough of it.

Women were more likely to say they had been told about local cancer support groups in their area than were men (referring to generic cancer groups rather than sarcoma groups).

Women were far more likely to use the national cancer charity websites than were men (particularly relating to the Macmillan Cancer Support, Cancer Research UK, and Sarcoma UK websites).

“\textit{I would have liked more help with coping, not being left to struggle on your own.}”

Clinical trials

Most patients were not asked if they wanted to take part in a clinical trial (67% overall). About 1 in 3 (32%) were asked. 28% of these were asked to take part in a trial at the hospital where they were being
treated and 4% were asked to take part in a clinical trial at another hospital.

Of those asked, 22% overall went on to take part in a trial.

Younger people were much more likely to be asked if they would participate in a clinical trial than were older patients. 60% of sarcoma patients asked to participate in clinical trials were in the 16-34 age group.

There is significant difference in access to clinical trials for sarcoma patients in Scotland. Only 15% of sarcoma patients in Scotland were asked if they wanted to take part in a clinical trial compared to 33% in England (and this tended to be at the hospital where the patient was being treated). 10% of patients asked went on to participate in a clinical trial.

“I would like to see easier access to trials without the patient having to fight for it. Patients have enough to deal with without having to search the internet.”

**Key Findings**

**Were you asked if you wanted to take part in a clinical trial?**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Yes, a clinical trial at the hospital where I was treated</th>
<th>Yes, a clinical trial at another hospital</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-34 yrs</td>
<td>60%</td>
<td>30%</td>
<td>10%</td>
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<tr>
<td>35-44 yrs</td>
<td>45%</td>
<td>25%</td>
<td>30%</td>
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<tr>
<td>45-54 yrs</td>
<td>30%</td>
<td>15%</td>
<td>55%</td>
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<tr>
<td>55-64 yrs</td>
<td>20%</td>
<td>10%</td>
<td>70%</td>
</tr>
<tr>
<td>65-74 yrs</td>
<td>10%</td>
<td>5%</td>
<td>85%</td>
</tr>
<tr>
<td>75-84 yrs</td>
<td>5%</td>
<td>2.5%</td>
<td>92.5%</td>
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<tr>
<td>85+ yrs</td>
<td>0%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>All sarcomas</td>
<td>40%</td>
<td>20%</td>
<td>40%</td>
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3. Post-treatment

The survey asked patients about their experiences post-treatment, including rehabilitation and follow up, as well as their concerns after treatment.

Rehabilitation services

We asked patients about which rehabilitation services they were referred to; the extent to which the rehabilitation service had helped; and which rehabilitation services the patient was not referred to which they think would have been helpful.

“Thanks to the skills of the surgeons the sarcoma was removed, my thumb was saved and with the help of the physiotherapist I have nearly achieved full use of my hand, for this I am eternally grateful.”

The most common services referred to were: physiotherapy, occupational therapy, dietetics, prosthetics, and wheelchair services.

“Dietary advice after my operation would have been helpful as the operation necessitated removal of part of my colon.”

“The effects of treatment in the long term is difficult to live with. My arm has limited movement. I have not been offered any physiotherapy to help me. I am still waiting 18 months on!”

Referral to rehabilitation services was much more frequent for bone sarcoma patients than for soft tissue sarcoma patients. In respect of every service (other than

At the end of your treatment, were you referred to any of the following rehabilitation services?*

*Most common referrals only
lymphoedema), bone sarcoma patients were much more likely to be referred. For example, 56% of bone sarcoma patients were referred for physiotherapy, but only 25% of soft tissue sarcoma patients were referred to that service.

Bone sarcoma patients were more positive about the impact of rehabilitation in helping them cope with the consequences of their treatment than were soft tissue sarcoma patients. 63% of bone sarcoma patients said the rehabilitation services had helped a lot, but only 48% of soft tissue sarcoma patients said this was the case.

Of all those who were referred for rehabilitation, 15% said the service had not helped them at all, and a further 32% said they had helped only a bit, indicating that almost half of sarcoma patients surveyed did not have a positive experience from their rehabilitation.

For both groups of patients, physiotherapy was regarded as the service which was most likely to have been helpful had it been received.

There is evidence that referrals to rehabilitation services drop as patients get older. For all services except lymphoedema and prosthetics, younger people are more likely to be referred than older patients. Younger patients were far more likely to be referred for physiotherapy and occupational therapy support than were older patients.

**Follow up**

Most patients (87% overall) said the information given to them about how their treatment would be followed up was clear.

90% of patients overall knew how to contact the sarcoma team at the hospital if they needed further information or help.

The most frequent time points for follow up were at 3 months and 6 months but there were differences between bone and soft tissue sarcoma patients on this. Bone sarcoma patients tended to be followed up more frequently with shorter time gaps than was the case for soft tissue sarcoma patients. 28% of bone sarcoma patients were followed up every month or two months, whereas only 13% of soft tissue patients were followed up as frequently. A very small number of patients said they were never followed up at all (1% of bone sarcoma patients, 3% of soft tissue sarcoma patients) which needs further investigation.

Awareness of how to contact the specialist sarcoma team at the hospital was lower amongst the oldest age group of patients.
“An improvement could be the establishment of joint follow up clinics with both sarcoma specialist surgeons and oncologists. I had this for a while, but they were each from a different NHS trust and while there was good co-operation amongst medical staff, the trusts had difficulty agreeing who was going to pay and consequently the joint sessions stopped.”

Post-treatment concerns

There was agreement between bone sarcoma patients and soft tissue sarcoma patients on what they were most worried about after the treatment finished. 71% in each group said they were worried about their cancer coming back. 49% of bone sarcoma patients said they were concerned about disability caused by surgery.

Worries post-treatment were far more pronounced in the youngest age group, irrespective of what those worries were.

When treatment finished, what were you most worried about?*

Key Findings

After treatment finished, women were more likely to be concerned about dying, why they got this cancer, and loss of control over their life, than were men. Men were more concerned than women about financial issues.
Diagnostic Tool – is it soft tissue sarcoma?

All patients with suspected/diagnosed soft tissue sarcoma refer to a Sarcoma Specialist Centre.

Clinical presentations
- Lump bigger than a golf ball (>4cm)
- Lump increasing in size
- Deep to the fascia

Investigations

Adults
- Refer for urgent ultrasound (performed within 2 weeks)
- Refer for urgent appointment (within 2 weeks) to a sarcoma specialist centre if scan suggests soft tissue sarcoma or if findings are uncertain and clinical concern remains

Children
- Refer for very urgent ultrasound (performed within 48 hours)
- Refer for very urgent appointment (within 48 hours) to sarcoma specialist centre if scan suggests soft tissue sarcoma or if findings are uncertain and clinical concern remains

Note: MRI is more effective for investigating large deep lumps. MRI & biopsy (fine needle) should only be performed under the direction of a sarcoma specialist centre.

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Sarcoma Specialist Centres: Soft Tissue

1. North of England Bone & Soft Tissue Tumour Service
   Newcastle Teaching Hospitals NHS Foundation Trust

2. Greater Manchester & Oswestry Sarcoma Service (GMOSS)
   Robert Jones & Agnes Hunt Orthopaedic Hospital Oswestry,
   Manchester Royal Infirmary, The Christie NHS Foundation
   Trust Manchester

3. Liverpool Sarcoma Service
   Royal Liverpool & Broadgreen University Hospitals Trust

4. Leeds Regional Sarcoma Service
   Leeds Teaching Hospitals NHS Foundation Trust

5. Sheffield Sarcoma Unit
   Sheffield Teaching Hospitals NHS Foundation Trust

6. Royal Orthopaedic Hospital NHS Foundation
   Birmingham

7. The Midlands Abdominal & Retroperitoneal Sarcoma Unit
   University Hospitals Birmingham NHS Foundation Trust

8. East Midlands Sarcoma Service
   Nottingham University Hospital
   Royal Infirmary

9. The Oxford Sarcoma
   Nuffield Orthopaedic

Further Information

- British Sarcoma Group guidelines
- sarcoma.org.uk/health-professionals/sarcoma-specialist-centres

10. Bristol Sarcoma Service
    North Bristol NHS Trust

11. Exeter Sarcoma Service
    Royal Devon & Exeter NHS Foundation Trust

12. Plymouth Hospitals NHS Trust

13. The London Sarcoma Service
    University College London Hospitals NHS Foundation Trust, Royal National Orthopaedic Hospital NHS Trust

14. The Royal Marsden Hospital

15. South West Wales Sarcoma Multi-Disciplinary Team
    South West Wales Cancer Network

16. North Wales refer to Greater Manchester & Oswestry Sarcoma Service

17. Northern Ireland Local Sarcoma Cancer Committee
    Musgrave Park Hospital, Belfast City Hospital,
    Royal Victoria Hospital, Mater Hospital Belfast,
    Ulster Hospital, Dundonald

Lumps, Bumps & Sarcomas: a guide

learning.bmj.com/sarcoma

FREE access for GPs, GPTrainees, hospital doctors & foundation doctors

Complete in your own time

Uses interactive clinical case studies and images that draw on latest research and clinical guidelines

Peer-reviewed
Discussion and Recommendations

There are six areas that are key drivers for a positive patient experience. Changes across these areas could help bring about significant improvements in patient experience. This section sets out ideas and gives details of the resources currently available to support change.

1. Early suspicion of sarcoma

GPs play a key role in starting sarcoma patients on the right route to prompt diagnosis and treatment. Whilst education initiatives to help GPs recognise the early signs and symptoms of sarcoma are in place (and are increasingly popular), the survey highlights that many GPs do not suspect sarcoma, resulting in delayed/inappropriate referral and treatment. The data highlights that a third of patients were started on treatment for something else. This may have been inappropriate surgery in general practice or secondary care, which could impact on long-term prognosis and future quality of life.

However, the survey also highlights that patients themselves delay presentation to their GP with symptoms, with the longest delays being patients with bone sarcoma. It is extremely concerning that 17% of bone sarcoma patients had symptoms for a year or more before seeing a GP.

- Include red flag sarcoma symptoms in national government and charity-led public and health professional awareness programmes on early diagnosis of cancer.
- Prioritise the inclusion of sarcoma in local and national GP education programmes.
- Ensure GPs know about accredited learning tools for sarcoma through engagement with key providers of GP training.
- Include sarcoma in medical student training.

- Open access BMJ Learning module on Lumps, Bumps and Sarcomas, sponsored by Sarcoma UK.
- Sarcoma UK’s On the Ball awareness campaign for GPs.
- Sarcoma UK’s Diagnostic Tool for GPs.
2. **Streamlined routes into sarcoma specialist services**

The current model of sarcoma care involves complex pathways from GPs in primary care to sarcoma diagnostic services, treatment and follow-up, as well as to rehabilitation and palliative care services. This reflects the complex nature of sarcoma itself. However, improvements could be made in the operation of these pathways, in particular identifying where the responsibility for development, implementation, and monitoring sits. There is potential for sarcoma services to take a more proactive approach to implementing and auditing pathways, to bring about improvements. The NICE Quality Standard for Sarcoma states that Sarcoma MDT’s should publish information about their shared pathways, activity and patient outcomes, including information on site-specific sarcoma (Statement 3), January 2015.

- Ensure GPs know how and where to refer patients with suspected sarcoma.
- Sarcoma Advisory Groups and sarcoma multi-disciplinary teams to take responsibility for the development of clear and effective pathways to sarcoma diagnostic and treatment centres and their publication and promotion.
- Sarcoma Advisory Groups and sarcoma multi-disciplinary teams to proactively establish links with local primary care and promote referral pathways into sarcoma diagnostic and treatment centres.
- Utilise technology and tools such as websites to promote pathways into sarcoma services, shared care arrangements, and to publish information about their services including MDT members.
- Sarcoma Advisory Groups and sarcoma multi-disciplinary teams to take the lead on monitoring compliance against pathways and shared care protocols, communicating non-compliance to Trusts, and publishing audits of the effectiveness of pathways.
- More dedicated resources to be made available to Sarcoma Advisory Groups and sarcoma multi-disciplinary teams including administrative and technical support, and the release of specialist clinical time.
3. Clear navigation within sarcoma specialist services

Analysis of data in the survey shows that patients benefit from clear navigation when within sarcoma services to help them understand what is happening to them. This fits with the proposition that well informed patients report better outcomes after treatment than patients who say they are not well informed (cf. BMJ Quality and Safety 7th February 2014).

The most powerful variable associated with high scores given by patients in the survey was whether they had been given a written treatment plan that told them everything about their sarcoma treatment from start to finish. Those patients who had such a written plan were much more likely to be positive than those who had no such plan at all or who had only a partial plan. Sarcoma patients attend multiple hospitals and sites for their treatment. The open text comments indicate a confusion amongst patients about who is treating them and who is responsible for their care, often combined with poor communication between NHS centres. A personalised written treatment plan can help by setting out the people and hospitals involved throughout the patient’s time in NHS services. When combined with signposting to high quality information about sarcoma and emotional support services, it can provide enhanced levels of reassurance to patients. A clear understanding of what is happening to them helps patients to cope with the emotional impact of a sarcoma diagnosis.

Having a sarcoma clinical nurse specialist (CNS) is also a key factor in ensuring that patients feel supported and informed throughout their treatment and recovery. 10% of patients in this survey did not have a CNS involved in their care at any time during their treatment which points to gaps in provision in some parts of the country.

- Sarcoma UK’s website pages for health professionals which includes a map of sarcoma specialist centres in the UK.
  www.sarcoma.org.uk/health-professionals
Discussion and Recommendations

Ideas

• Provide every patient with a written treatment plan that includes:
  – Names and contact details of the people responsible for their treatment and care
  – Details of where their treatment will be delivered
  – Point of contact (CNS and key worker)
  – Information about the sarcoma multi-disciplinary team model and sarcoma expertise within its members
  – Details of sarcoma-specific sources of information and emotional support.

• Sarcoma UK to pilot a written treatment plan template with sarcoma specialist centres.

• Close gaps in sarcoma CNS provision through increased allocation of resources, to provide consistency of contact, and cover during absence.

Resources

• Sarcoma UK’s Toolkit for newly diagnosed patients.

• Sarcoma UK’s range of patient information which contain a section for adding in personalised information (Information Standard accredited).


4. Emotional support

It is clear from the data that there are gaps in the provision of emotional support for patients with sarcoma, and this is more pronounced for younger patients and those with soft-tissue sarcoma. Over a third of respondents wanted more emotional support.

Only small numbers of sarcoma patients were signposted to support and information services specifically set up for sarcoma. This is not because these types of service are unavailable. There is an established network of local sarcoma support groups in the UK; online patient support forums; personalised support by phone and email; and accredited websites and printed patient information provided free of charge by national sarcoma charities. It points more to a lack of knowledge of these sarcoma patient support services by clinical teams. This is an area where change could be easily implemented with immediate improvement to patient experience.
5. Access to specialist sarcoma rehabilitation services

The data highlights significant inequalities in access to rehabilitation services and the benefit received, in particular for older patients and patients with soft tissue sarcoma. Younger patients were six times more likely to be referred to rehabilitation services following their treatment.

Almost half of patients with soft tissue sarcoma who used rehabilitation services didn’t find they helped much. This may be because patients with soft tissue sarcoma have less access to specialist sarcoma rehabilitation services such as physiotherapy, that are a key feature at the nationally funded bone sarcoma centres. Instead, they may receive their rehabilitation locally, for example from non-sarcoma physiotherapists, which may result in less positive outcomes.
Patient experience of rehabilitation could be improved by patients and clinicians having a shared understanding of what can realistically be achieved through rehabilitation, and discussing expectations of rehabilitation at the earliest possible opportunity. Clinicians (in particular surgeons) and rehabilitation specialists have an important role to play in honestly discussing goals and the achievable level of physical function post-treatment with their sarcoma patients, using terminology that reflects 'real life'.

The complex multiple pathways for sarcoma may also result in gaps in access to rehabilitation services, with patients falling between hospitals without a main point of co-ordination. A more co-ordinated pathway to rehabilitation services combined with recognition of the importance of rehabilitation referrals for all age groups and types of sarcoma is key to improving patient experience.

**Ideas**
- Offer all patients with sarcoma a referral to appropriate rehabilitation services, irrespective of their age and type of sarcoma. Ideally, all sarcoma patients requiring rehabilitation services should be seen by a sarcoma rehabilitation specialist for initial assessment.
- Instigate honest conversations with patients, ideally pre-treatment, to discuss outcomes and expectations post-treatment and what can realistically be achieved through rehabilitation services.
- Consider national commissioning for sarcoma rehabilitation services.

**Resources**
- Sarcoma UK’s national Rehabilitation Hub. [www.sarcoma.org.uk/about-sarcoma/rehabilitation](http://www.sarcoma.org.uk/about-sarcoma/rehabilitation)
- Sarcoma UK’s factsheet *Rehabilitation for sarcoma patients*

### 6. Information about clinical trials

The survey indicates that the majority (67%) of sarcoma patients were not asked whether they wanted to take part in a clinical trial. Even when patients are asked, there was low uptake with only 22% going on to take part in trials.

Information about current available trials is not easy to find, and the challenge of keeping up to date with this information could be an important contributory factor to patients not being asked about participation. It is important to avoid assumptions
about the patient’s personal situation, for example, assuming that patients won’t be willing to travel to take part in a clinical trial. Evidence from this survey clearly shows that patients are willing to travel to receive the best treatment.

There was a significant variation in the age of patients asked to take part in trials, with an age bias towards younger people. This may be an inequality around access, or may reflect that many open trials at the time of this survey were for types of sarcoma that more commonly occurred in the younger age group, eg osteosarcoma, Ewing’s sarcoma, synovial sarcoma.

- Information about open clinical trials to be made more widely available to all sarcoma specialist centres and clinicians, so that they are aware of what is available outside their own centre.
- Sarcoma UK to develop a Clinical Trials Information Centre, containing detailed information about open clinical trials and opportunities for patients to get involved in research.
- Consider a broader question such as “do you want to take part in sarcoma research” during consultations. This may encourage more patients to participate, and avoids the perception of participation in clinical trials as a ‘last resort’.
- Always consider the older age group of sarcoma patient. They may be equally applicable for entry to a clinical trial, willing to take part, and could make a significant contribution to the numbers of patients taking part in sarcoma research.

- A list of open clinical trials for sarcoma: www.sarcoma.org.uk/support-information/clinical-trials that signposts to further information.
The National Sarcoma Survey 2015 – Transforming patient experience

Leroy Duffus, sarcoma patient
Scotland Sarcoma Patient Experience Survey

Methodology

Data was collected from patients treated in both England and Scotland. England patients were recruited from the three most recent iterations of the National Cancer Patient Experience Survey (NCPES) 2010-14, from those who said they were prepared to accept further questionnaires about their healthcare, and who had survived in to the fieldwork period in 2015. Scotland data was collected from patients who attended for treatment in specific hospitals treating sarcoma patients by way of staff distributing questionnaires in clinic. The sizes of the two response groups were very different, with 558 respondents in England (of 900 questionnaires distributed, 64% response rate) and 92 in Scotland (from 305 packs distributed to hospital clinics, with an indeterminate number distributed to patients). However, there are a substantial number of statistically significant differences in scores between England and Scotland. The Scottish data shows poorer scores on almost all questions where there are such differences.

There are 8 questions on which there are statistically significant differences between the scores given by sarcoma patients in England and in Scotland. T tests for groups of respondents of differing sizes were used to analyse the data.

On 5 of these questions, patients in England were more likely to be positive than were patients in Scotland, especially in relation to the most important drivers of high patient scores in this survey - the provision of written treatment plans and being told that they may have a sarcoma by the GP or A&E doctor. However, patients in Scotland were more likely to have a CNS in charge of their care at all times, partly because patients in Scotland tended to be treated at the same hospital for radiotherapy, chemotherapy, and operations.

Key findings

Specialist sarcoma teams

80% of sarcoma patients in Scotland were treated by a specialist sarcoma team.

Clinical nurse specialists (CNS’)

Sarcoma patients in Scotland were more likely to have the same CNS in charge from start to finish.
Complex pathways

Patients in Scotland were more likely to receive all their treatment at the same hospital. Only 11% of patients in Scotland went to more than one hospital for treatment, compared to 38% of patients in England.

Written treatment plan

Sarcoma patients in Scotland were less likely to be given a written treatment plan that told them everything from start to finish. Only 34% of patients were given a written plan.

Clinical trials

There is significant difference in access to clinical trials for sarcoma patients in Scotland. Only 15% of sarcoma patients in Scotland were asked if they wanted to take part in a clinical trial compared to 33% in England (and this tended to be at the hospital where the patient was being treated). 10% of patients asked went on to participate in a clinical trial.
Appendix B

The National Sarcoma Patient Experience Survey
Expert Panel

Lesley Abraham
Soft tissue sarcoma patient; support group leader (Merseyside & Cheshire)

Dr Robin Jones
Consultant Medical Oncologist at Royal Marsden, London; Team Leader in Sarcoma Clinical Trials at Institute of Cancer Research

Jordan Anderton
Soft tissue sarcoma patient

Claire Kelleher
Head of Information & Support, Sarcoma UK

Lindsey Bennister
Chief Executive, Sarcoma UK

Helen Stradling
Sarcoma Advanced Nurse Practitioner, The Oxford Sarcoma Service

Michael Maguire
Consumer representative, NCRI sarcoma clinical studies group.

Dr Rachel Taylor
Senior Research Manager, Cancer Clinical Trials Unit, University College London Hospitals

Ceinwen Giles
Founder, Shine Cancer Support (for younger adults with cancer)

Dr Reg Race
Quality Health

Mr Jonathan Gregory
Orthopaedic Oncology Surgeon, Greater Manchester and Oswestry Sarcoma Service

Andy Roast
Bone sarcoma patient

Professor Winette van der Graaf
Professor of Personalised Oncology & Sarcoma Research at Institute of Cancer Research; Consultant Medical Oncologist at Royal Marsden, London

Professor Jeremy Whelan
Consultant Medical Oncologist, London Sarcoma Service

Tony Grover
Soft tissue sarcoma patient; support group leader (Norfolk)

Roger Wilson CBE
Soft tissue sarcoma patient, Founder Sarcoma UK