

Delays cost lives

A call to policy
makers to improve
early diagnosis
of sarcoma



SarcomaUK

The bone & soft tissue
cancer charity

#SarcomaWontWait

What is sarcoma?

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.

About 15 people are diagnosed with sarcoma every day in the UK. That's 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).

Sarcoma diagnoses make up about 1.4% of all cancer diagnoses in the UK.

About Sarcoma UK

Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments. It is the only cancer charity in the UK focusing on all types of sarcoma.

Our policy team looks for evidence to develop policy that will influence key decision makers in the Government, NHS, and research communities. We want to make sure everyone affected by sarcoma has access to the best possible treatment and care.

Working across the UK to develop and drive policy solutions, we aim to bring about change by improving outcomes and services for patients with sarcoma.

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Forewords

“Put simply, late diagnosis costs lives.”



Richard Davidson
Chief Executive,
Sarcoma UK

At Sarcoma UK, our aim is that everyone who is affected by sarcoma gets the best outcome. At the core of this is ensuring that patients can be diagnosed as quickly as possible.

Being diagnosed with any cancer is an isolating and lonely experience, but this is further amplified for sarcoma patients who have agonisingly long waits for a diagnosis of a cancer that has such limited treatment options. The later that a cancer is diagnosed, there will be even fewer options available for treatment and a higher chance of treatments not working. Put simply, late diagnosis costs lives.

At Sarcoma UK, we are supporting more patients than ever through their diagnosis; calls to our Support Line about diagnosis increased by a third this year. However, support alone does not tackle the larger changes needed to improve time to diagnosis.

Unfortunately, we know from speaking to patients that their symptoms are often dismissed by primary healthcare professionals, being told they have a common benign condition such as a cyst or growing pains, without any follow up investigation. Even when patients return to healthcare professionals multiple times with worsening symptoms, they often come away with the same diagnosis, or if they are not scanned with the right expertise, the results are inaccurately read.

This, in conjunction with a lack of public awareness of sarcoma and its symptoms, means sarcoma patients regularly wait years to receive an accurate diagnosis, which is unfair and could be avoidable.

To help address this problem, this project has spent the past year focussing on the issues arising in sarcoma diagnosis, consulting patients, clinicians and other healthcare professionals to develop a set of recommendations to improve the time it takes to get accurate diagnoses.

We now need to work with policy makers to ensure these recommendations become a reality and collaborate with healthcare professionals to acknowledge and build on the gaps in knowledge and infrastructure that prevents sarcoma patients from reaching a quick and accurate diagnosis.

Sarcoma UK is committed to focussing on early diagnosis in the coming years. We will set up an Early Diagnosis Steering Group which will bring together the length and breadth of the sarcoma community to drive forward the recommendations.

This report signifies the first big step to improve early diagnosis for sarcoma. We will passionately work towards the goals it sets out so that all patients with sarcoma are diagnosed as early as possible, giving them the best chance of survival.

“...rare cancer isn’t that rare. A GP practice in the UK will see a sarcoma around once every two years.”



Jess Phillips MP

Member of Parliament for Birmingham Yardley and Shadow Minister for Domestic Violence and Safeguarding, and daughter of Jean Trainor

My mother Jean dedicated much of her working life to the NHS, making sure it stayed the incredible lifesaving service that it is. From local primary care organisations to working alongside national health planning bodies, her desire to improve the status quo was always apparent. However, when it came to being diagnosed with sarcoma cancer, she experienced first-hand the problems that hundreds, if not thousands, of people are faced with every year in the UK.

It took about a year before my mother was finally diagnosed with vascular leiomyosarcoma in 2008. She first noticed a swelling in her leg in the summer of 2007. After a hospital visit, she was told that it was due to deep vein thrombosis, and was prescribed blood thinners. However, despite being given this treatment, this diagnosis was never confirmed.

Over the next twelve months and countless trips back to the hospital later, she was told time and again to come back if it there was no improvement, which there never was. It took a tick bite in the south of France for someone to realise that something wasn't right. Within 10 days of visiting the doctor in France, the supposed deep vein thrombosis was diagnosed as a leiomyosarcoma tumour, and she had an operation to try to remove it.

Like many sarcomas, my mother was diagnosed much later than she could have been, meaning that the cancer had spread to her lungs. The archaic treatments, which are still in use today, did little to help.

I was lucky to have had time with my mother after her diagnosis, as she fought the odds to survive for three more years after being diagnosed. However, there was no excuse for her cancer not being caught earlier. When she raised this with the hospital, she was told 'We couldn't have discovered that the lump in your vein was a cancer [not a deep vein thrombosis] because it is extremely rare.' But rare cancer isn't that rare. Current data shows that 47% of cancers diagnosed are rare and less common cancers, and incidence statistics show that a GP practice in the UK will see a sarcoma around once every two years.

Sarcoma UK offered her great deal of support while she was alive, as they continue to do for many others affected by this cancer. The recommendations outlined in this report – many of which are as pertinent today as they were for my mother nine years ago – play a role in helping to make sure all sarcomas are diagnosed as early and accurately as possible.

No one should ever find themselves in my mother's position, but they will if change doesn't take place. The starting point for that begins here.

“I now find I have lung mets and my life is in danger. Do I think the NHS could have done a better job of avoiding my present predicament – of course I do.”

An excerpt from Jean's online blog

Executive Summary

All patients deserve the best chance at beating cancer. Unfortunately, this is not the picture we see for sarcoma patients, with widespread delays, misdiagnoses and repeated appointments, meaning that patients are spending months or even years not receiving the correct, if any, treatment.

This report, *Delays Cost Lives*, aims to outline how together we can change this story – by providing a foundation from which to influence policy makers, sparking a conversation about sarcoma among the public and healthcare professionals, and providing a voice for sarcoma patients to influence the future of diagnosis.

The report delivers a series of policy recommendations that ask government, public and professional bodies to take action to help improve a patient's journey to a sarcoma diagnosis, primarily through education, awareness and accessibility. By improving these three areas, we can give sarcoma patients a better chance of seeking help, having their symptoms recognised, being referred for imaging and receiving prompt treatment.

1 in 3

(30%) patients in the UK waited at least six months after first consulting a healthcare professional before receiving an accurate diagnosis for their sarcoma.⁴



Why focus on early diagnosis?

- Patients regularly tell us that it takes them a long time to get to the correct diagnosis, and/or they are given an incorrect diagnosis (and are recommended treatment for this).
- For soft tissue sarcomas, survival is determined by tumour size, grade and location.¹
- The only one of these factors that can be altered to improve outcome is the size of the tumour at diagnosis. By early detection we can catch tumours at a smaller size and improve outcomes.
- Catching sarcoma at an early stage also means that the cancer is less likely to have spread, increasing the chance of survival.
- Delays in diagnosis are also associated with increased risk of metastases, increased risk of amputation rather than limb salvage surgery² and may have an impact on a patient's opportunity for fertility preservation.³
- Sarcoma also brings a high emotional toll, which only increases with late or misdiagnosis. Patients have told us that it makes them blame themselves for not noticing symptoms or not pushing a healthcare professional further, and family members see the delays as a possible difference between life and death. In fact, our National Sarcoma Survey⁴ found that 9 out of 10 patients said sarcoma negatively affected their mental health and 1 in 4 said it had affected them severely.

1. Pisters, P. W., Leung, D. H., Woodruff, J., Shi, W. & Brennan, M. F. (1996). Analysis of prognostic factors in 1,041 patients with localized soft tissue sarcomas of the extremities. *J. Clin. Oncol. Off. J. Am. Soc. Clin. Oncol.* 14, 1679-1689

2. Clark MA, Thomas JM, (2005). Delay in referral to a specialist soft-tissue sarcoma unit. *Eur J Surg Oncol.* 2005;31(4):443-8.

3. Bradford NK, Walker R, Henney R, Inglis P, Chan RJ, (2017). Improvements in clinical practice for fertility preservation among young Cancer patients: results from bundled interventions. *J Adolesc Young Adult Oncol.*

4. Sarcoma UK National Patient Survey (2020). Unless specified statistics are based on our survey of adults 16+.

Demand Early Diagnosis, Save Lives

In June 2020, we released an interim report – Demand Early Diagnosis, Save Lives – which pledged to take action to improve early diagnosis.

The interim report highlighted three key themes: public awareness, healthcare professional knowledge and the quality and efficiency of scans and referrals.

It revealed the real impact of a lack of public awareness of symptoms, with many patients waiting months after their first symptoms before seeing a healthcare professional. It also identified the lack of awareness among primary care professionals, where there was a poor knowledge of signs and symptoms of sarcoma. Lastly, it tackled scans and referrals, acknowledging the importance of being treated by or with a specialist team and for diagnostic scans to be completed as quickly as possible.

How we built our evidence base

- We consulted patients, family members and clinicians to develop our early diagnosis policy recommendations. We conducted more than 60 conversations with individuals throughout the project to gain their insight at each stage.
- We brought together Patient Advisory Groups to discuss the recommendations from personal experience and to feed into our final policy goals.
- We commissioned a rapid literature review, consulting a variety of sources to identify existing literature on the subject and best practice for early diagnosis.
- We carried out the National Sarcoma Survey (2020) asking patients, carers and families about their experience of diagnosis.

Sarcoma UK are calling on policy makers to make faster and more accurate diagnosis a reality for the sarcoma community. We recommend that:

- 1** A sarcoma education programme for healthcare professionals should be rolled out, placing importance on the individual impact of sarcoma and how it is important to rule it out, not rule it in.
- 2** We need to raise awareness of sarcoma and its symptoms. Sarcoma can occur anywhere in the body and it is vital that the public are aware of this.
- 3** Ensure that there are clear and efficient referral pathways that allow primary healthcare professionals to access the optimum route for all their patients.

These recommendations are targeted at policy makers to help improve diagnosis for sarcoma patients in the UK. Each recommendation aims to put sarcoma on the agenda for future policy decisions, and uses existing platforms to enhance and spread awareness of sarcoma. As a whole, these recommendations not only aim to make changes to policy, but also aim to simulate work on early diagnosis, both for Sarcoma UK and in coalition with other organisations.

Introduction

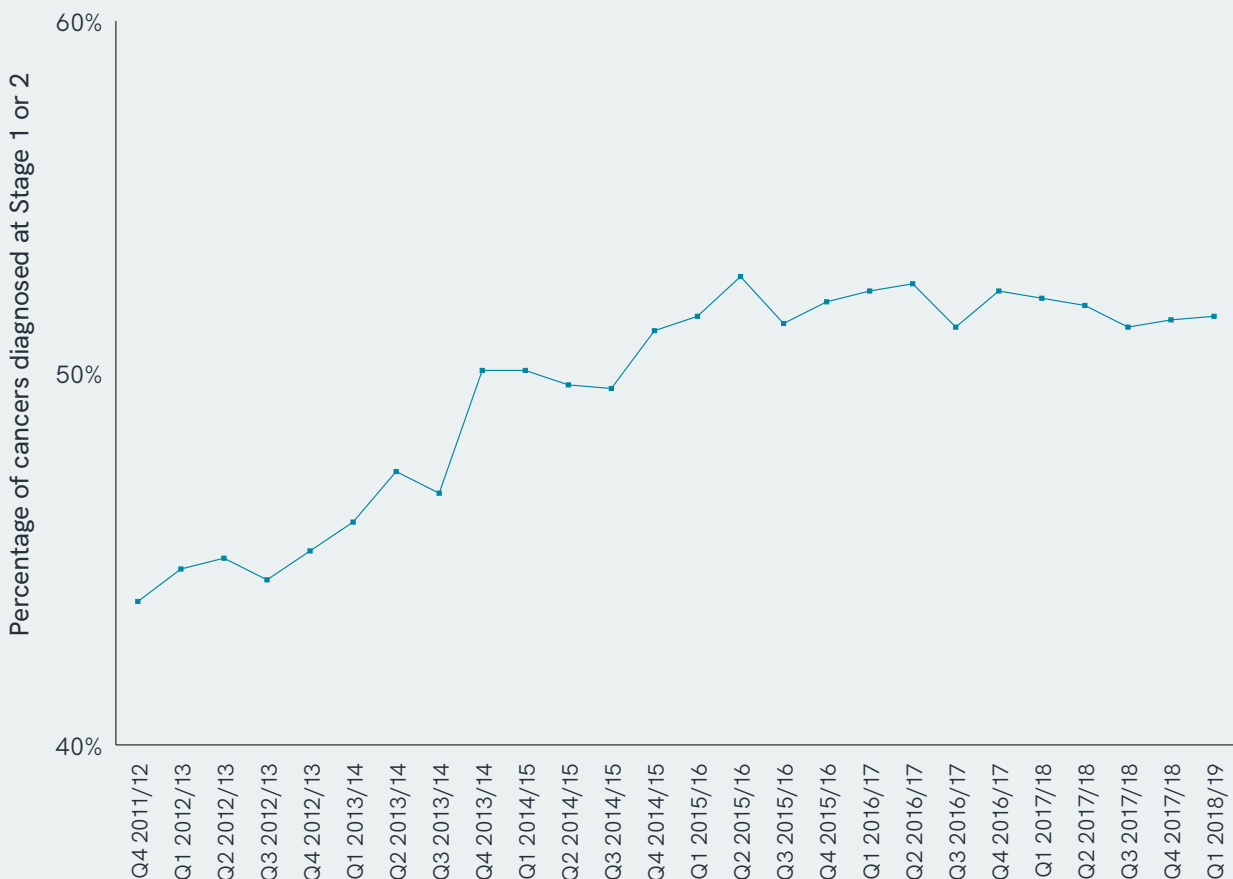
Background on Cancer Diagnosis

Early diagnosis aims to catch cancer sooner, and reduce the number of patients who are diagnosed at a later stage. It is commonly accepted that Stages 1 and 2 are considered to be early stages, as the cancer has not spread to anywhere else in the body. Once the cancer has spread then chances of survival significantly decrease⁵ and it is less likely they will have the chance of a complete cure.

Data from Public Health England shows that the figures for the diagnosis of all cancers at Stage 1 and 2 are slowly increasing with 44.8% of patients being diagnosed at these stages in the first quarter of 2012/13 compared to 51.8% in the first quarter of 2018/19, 6 years later.

Although any progress is positive, this rate of improvement will not meet the goal of the NHS Long Term Plan to diagnose three in four cancers (75%) at an early stage by 2028.⁶

There is a lack of clinical data available for sarcoma, which means that it is hard to determine at what stage the majority of sarcomas are diagnosed. Only around a quarter of sarcomas had this staging data reported in 2018, so even if the NHS Long Term Plan goal is met it is unlikely that this figure will be representative for sarcoma patients.



Source: Public Health England, National Cancer Registration & Analysis Service

Early diagnosis and sarcoma

Although NHS data for sarcoma diagnosis is sparse, we can identify a number of barriers to early diagnosis.

Data from Sarcoma UK's National Sarcoma Survey 2020 finds that there is a significant delay in reaching a sarcoma diagnosis after a patient presents to a healthcare professional with symptoms, with nearly 1 in 3 sarcoma patients waiting over 6 months to be diagnosed. This length of time decreases the chances of treating sarcoma at an early stage.

We know that with around 160 subtypes of sarcoma there is great range of symptoms, making the chance of early diagnosis for some subtypes particularly low. For example, GIST patients do not often experience any specific signs and symptoms, or even if they do these will be vague, such as fatigue and nausea. However, there are a number of more common symptoms that make many sarcoma subtypes easier to identify; for example, the National Sarcoma Survey found that 34% of patients had a painless lump and 26% had a lump that was increasing in size.

There are currently no tests or biomarkers that can determine whether you have sarcoma before it causes noticeable symptoms, however, further research into this area may identify solutions for this.

1 in 3

sarcoma patients wait over 6 months to be diagnosed after their initial appointment with a healthcare professional.



Early diagnosis initiatives

Early diagnosis of cancer is in the forefront of health policymakers' minds, with long-term commitments having been made to improve early diagnosis from the NHS, public health bodies and the Department of Health and Social Care. However, most of these programmes look to target cancer as a whole, or more common cancers, meaning their applicability to sarcoma is often low.

The NHS's Long Term Plan provides an overall commitment to help improve early diagnosis. It states that from 2028, an extra 55,000 people each year will survive for five years or more following their cancer diagnosis and that three in four cancers (75%) will be diagnosed at an early stage.⁷ To help achieve this a number of methods have been adopted, but sadly, overarching attempts to improve cancer diagnosis to date have had little-to-no effect on sarcoma.⁸

Public Health England's 'Be Clear on Cancer' campaigns aim to improve early diagnosis of cancer by raising public awareness of signs and/or symptoms of cancer, and to encourage people to see their GP without delay. This has seen a number of tumour-specific campaigns being run such as on bowel and lung cancer⁹ but has left a gap on less common cancers such as sarcoma.

In the clinical setting, Rapid Diagnostic Centres (RDCs) have been designed to speed up cancer diagnosis for patients with non-specific symptoms. We are yet to see the quantitative effect of this on sarcoma but with the variety of symptoms that it can have we hope this will be positive.

The new Faster Diagnosis Standard was introduced in April 2020 (although NHS trust won't be measured against the new standard during the Covid-19 outbreak) to ensure that all patients who are referred for the investigation of suspected cancer find out, within 28 days, whether they do or do not have a cancer diagnosis. This should have a positive impact on waiting times once on a sarcoma pathway, however, it will not improve time to diagnosis for those who are misdiagnosed with more common conditions such as cysts or growing pains.

The Cancer Workforce Plan was jointly developed to ensure the NHS in England has the right numbers of skilled staff to provide high quality care and services to cancer patients at each stage in their care. Phase one found that good progress was made on upskilling to increase workforce capacity to support earlier diagnosis

“I feel so passionate about telling my daughter’s story, and about how utterly traumatising it was not to have a medical professional listen to your concerns as a frightened parent when your child obviously has a serious problem.”

Katie, whose daughter Alyssa was 6-years-old when she was diagnosed with orbital rhabdomyosarcoma

of cancer.¹⁰ However, there has been limited impact on sarcoma and more focus needs to be placed on the ability to detect symptoms by clinicians who are in contact with sarcoma patients prior to their referral to a specialist centre.

Variations in Early Diagnosis of Sarcoma

Time to diagnosis can vary greatly depending on the subtype of sarcoma, the location in the body and the patient’s geographic location. Both the Sarcoma Service Specification and the NICE guidelines (evidence-based recommendations for health and care in England) provide some uniformity but vast differences in time to diagnosis remain.

Due to the number of subtypes of sarcoma and their heterogeneity in symptoms, as well as the nature of sarcoma in developing in many different sites in the body, there is a great deal of variation in how quickly it can be diagnosed. Sarcomas which are visibly large and painful are likely to be investigated quicker than those that have vague or no visible symptoms.

The rarity of the type of the sarcoma may also influence healthcare professionals’ likelihood of prompt diagnosis. For these rarer types of sarcoma, the symptoms are often different to those laid out in the NICE guidelines. For example, Kaposi’s sarcoma and dermatofibrosarcoma protuberans (DFSP) occur in the skin, compared to GISTs which start in the digestive system.¹¹ Diagnosis of sarcoma can also greatly vary dependent on geographical region. There are 17 sarcoma centres across the UK but these all have varied pathways and catchment areas.

There is a substantial difference in the average duration of symptoms of different subtypes of sarcoma prior to diagnosis:

Bone sarcoma:	
osteosarcoma	12 weeks
chondrosarcoma	52 weeks
Ewing sarcoma	20 weeks
spindle cell sarcoma	20 weeks
Soft tissue sarcoma:	
liposarcoma	28 weeks
leiomyosarcoma	26 weeks
malignant fibrous histiocytoma	20 weeks
synovial sarcoma	52 weeks
malignant peripheral nerve sheath tumour	26 weeks ¹²

Further variation is also likely to be found earlier on in the diagnostic pathway, where there is varying knowledge of sarcoma among primary care professionals and in their access to the appropriate imaging.

Diagnosis of sarcoma can also greatly vary dependent on geographical region. There are 17 sarcoma centres across the UK but these all have varied pathways and catchment areas.

UK sarcoma specialist centres



England

Bone and soft tissue specialist centres:

1. North of England Bone and Soft Tissue Tumour Service/ Newcastle Teaching Hospitals NHS Foundation Trust
2. Greater Manchester and Oswestry Sarcoma Service (GMOSS)/ Robert Jones and Agnes Hunt Orthopaedic Hospital Oswestry/Manchester Royal Infirmary/The Christie NHS Foundation Trust Manchester
3. Royal Orthopaedic Hospital NHS Foundation Trust Birmingham
4. OXSARC - The Oxford Sarcoma Service/ Nuffield Orthopaedic Centre
5. The London Sarcoma Service/ University College London Hospitals NHS Foundation Trust/ Royal National Orthopaedic Hospital NHS Trust

Soft tissue specialist centres:

6. Liverpool Sarcoma Service/ Royal Liverpool & Broadgreen University Hospitals Trust
7. Leeds Regional Sarcoma Service/ Leeds Teaching Hospitals NHS Foundation Trust. Bone sarcomas referred to Royal Orthopaedic Hospital Birmingham.

8. Sheffield Sarcoma Unit/ Sheffield Teaching Hospitals NHS Foundation Trust. Bone sarcomas referred to Royal Orthopaedic Hospital, Birmingham & Royal National Orthopaedic Hospital NHS Trust, Stanmore.
9. The Midland Abdominal & Retroperitoneal Sarcoma Unit/University Hospitals Birmingham NHS Foundation Trust.
10. East Midlands Sarcoma Service/Nottingham University Hospital NHS Trust/University Hospitals of Leicester NHS Trust. Bone sarcomas referred to Royal Orthopaedic Hospital Birmingham.
11. Bristol Sarcoma Service/ North Bristol NHS Trust. Bone sarcomas are referred to the Oxford Sarcoma Service.
12. Plymouth Hospitals NHS Trust. Exeter Sarcoma Service
13. Exeter Sarcoma Service/ Royal Devon & Exeter NHS Foundation Trust.
14. The Royal Marsden Hospital. The London Sarcoma Service. Bone sarcomas referred to Royal National Orthopaedic Hospital NHS Trust.

Wales

(2.) North Wales. All soft tissue and bone sarcomas are referred to Greater Manchester and Oswestry Sarcoma Service (GMOSS).

15. South Wales Sarcoma Multi-Disciplinary Team. Bone sarcomas referred to Royal Orthopaedic Hospital Birmingham.

Northern Ireland

16. Sarcoma Multi-Disciplinary Team. Bone sarcomas and soft tissue sarcomas are diagnosed and treated across a number of hospitals including Musgrave Park Hospital Belfast, Ulster Hospital Dundonald, and Belfast City Hospital.

Scotland

17. Scottish Sarcoma Network soft tissue and bone sarcomas are treated at the following regional centres:

Aberdeen
Dundee
Edinburgh
Glasgow
Inverness

Aims of the Project

This project aims to develop a set of policy recommendations that will allow Sarcoma UK to advise policy makers to improve early diagnosis of sarcoma, and engage with policy officials on the appropriate prioritisation of the early diagnosis of sarcoma.

By conducting consultations with both our patient and clinical community, we have been able to add weight behind these recommendations and identify what stages of the patient journey we need to target to minimise delayed diagnosis.

Overall, this project has three key objectives:

- 1** To provide a voice for sarcoma patients, sharing their stories and experiences demonstrating the impact of late diagnosis of sarcoma.
 - 2** To be a building block to influence future policy engagement with government, public and professional bodies on early diagnosis, ensuring that we can work collaboratively and produce tangible improvements for sarcoma patients.
 - 3** To spark conversations about sarcoma among both the public and healthcare professional community, using this momentum to begin to implement the recommendations.
-

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

Sue Mutch, who was diagnosed with synovial sarcoma five years ago

Scope of the project

The project focuses on making an impact across the UK. Although our research draws primarily on initiatives that have been set up in England, we have consulted with clinicians from across the UK to ensure their broad structure can be used as a model across the UK.

The recommendations should apply to patients with all types of sarcoma. Our patient group represented people with both soft tissue sarcoma (including GIST) and bone sarcoma.

The recommendations should apply to patients of all ages, although age-related factors will need to be considered. Those consulted were all adults so to confirm their applicability for children, further research may be needed.

The recommendations should provide ways of improving early diagnosis in all regions, for all sarcoma patients, but they may be applied differently, dependent on how specific Cancer Alliances and Trusts operate.

Consultees were self-selecting from a group of people we contacted and all had previously interacted with Sarcoma UK, therefore this may not have been representative of all sarcoma patients, families and healthcare professionals.

This is the first time any UK organisation representing all sarcomas has conducted an in-depth qualitative piece of research into early diagnosis. It is our hope that these findings provide a foundation to influence future policy and research in this area.

5. Nuffield Trust (2020). Cancer survival rates. Available from: nuffieldtrust.org.uk/resource/cancer-survival-rates.

6. NHS England (2019). Diagnosing cancer faster and earlier. Available from: england.nhs.uk/cancer/early-diagnosis/#:~:text=Early%20detection%20%E2%80%93%20new%20screening%20tests,-Bowel%20cancer%20screening&text=If%20it%20is%20detected%20at,use%20than%20the%20previous%20test.

7. *ibid*

8. George, A. & Grimer, R, (2012). Early symptoms of bone and soft tissue sarcomas: could they be diagnosed earlier? *Ann. R. Coll. Surg. Engl.* 94, 261-266

9. Cancer Research UK (2020). Be Clear on Cancer. Available from: cancerresearchuk.org/health-professional/awareness-and-prevention/be-clear-on-cancer.

10. NHS Health Education England (2019). Progress update- Update on Phase 1 of the Cancer Workforce Plan. Available from: hee.nhs.uk/our-work/cancer-workforce-plan.

11. Cancer Research UK (2018). Soft tissue sarcoma. Available from: cancerresearchuk.org/about-cancer/soft-tissue-sarcoma/types.

12. Smith, G.M., Johnson, G.D., Grimer, R.J. & Wilson, S. (2011). Trends in presentation of bone and soft tissue sarcomas over 25 years: little evidence of earlier diagnosis. *Annals of the Royal College of Surgeons of England*. [Online]. 93 (7). pp. 542-7. Available from: [ncbi.nlm.nih.gov/pubmed/22004638](https://pubmed.ncbi.nlm.nih.gov/pubmed/22004638).

Approach

Impact of Sarcoma: National Sarcoma Survey 2020 results

Following the insights gathered through our previous national survey in 2015, Sarcoma UK decided to run a new survey in 2020 with a broadened purpose: to collect data on sarcoma patient experience in order to build an evidence-base for influencing. A core part of this dataset focused on patients' experience of diagnosis. This data has allowed us to build a clear picture of the diagnostic landscape and has provided us robust evidence to develop policy on early diagnosis.

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

Both the National Sarcoma Survey and a YouGov poll of the public found that awareness was low, with 79% of sarcoma patients being unaware of sarcoma before their diagnosis and 75% of the public similarly not having heard of sarcoma, respectively. Even among the 25% of people who had heard of sarcoma, 30% did not know what the symptoms are.

The National Sarcoma Survey also found that GPs do not associate the symptoms that patients described with 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.

In addition, delays in diagnosis were also common: 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.

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.

1,117
responses to the survey

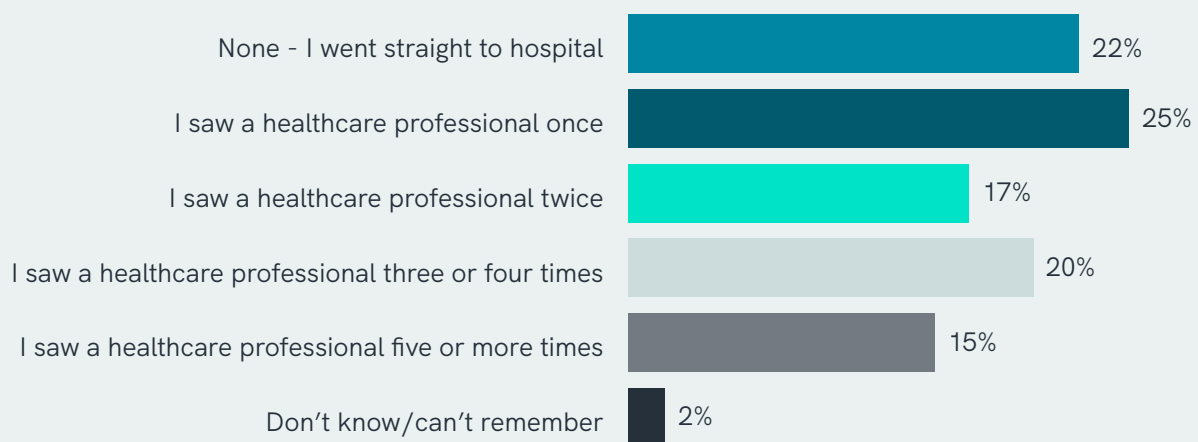
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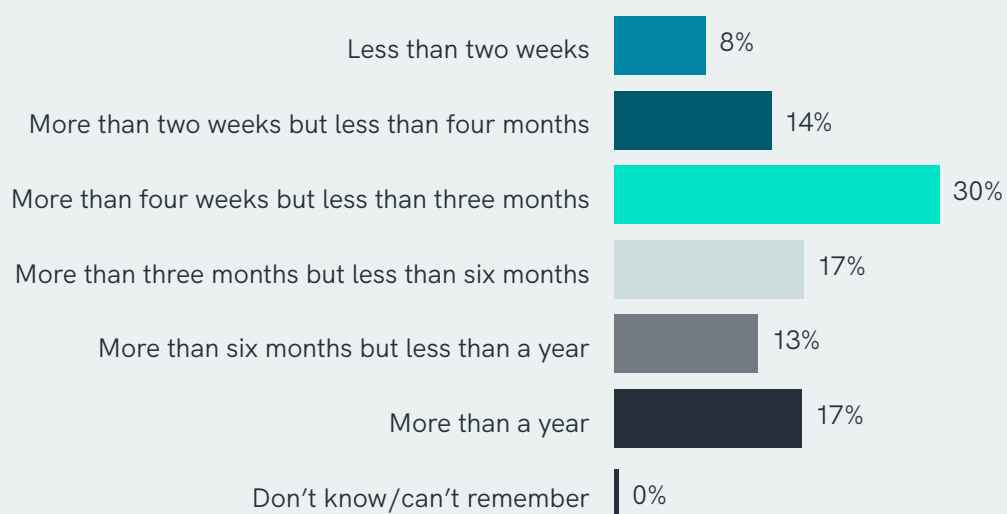
Around a third of respondents (30%) took more than 6 months to receive an accurate diagnosis, with 17% waiting more than a year.

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?

Time between patient first visiting GP/A&E and receiving accurate diagnosis



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

Literature Review

We commissioned a rapid literature review to assess the existing literature on the diagnosis of sarcoma. This review included a variety of sources, including peer-reviewed journal articles, clinical trials and grey literature from cancer advocacy and government health bodies.

The review further exposed the lack of awareness of sarcoma and its symptoms among the public and healthcare professionals. Findings suggest that most patients initially contacted their GP, but many healthcare professionals lacked awareness due to low familiarity with guidelines and their application, and the absence of adequate training.

In terms of public awareness, the review identified an immediate need for awareness-raising campaigns about symptoms, empowering people to seek medical advice and providing positive information about the value of early and effective public education.

It also highlighted the importance of the establishment of clear referral pathways to enhance access to expert diagnosis and treatment for sarcoma.¹³ Simple and clear guidelines, and knowledge of and adherence to these, would help those in primary care to accurately refer sarcoma patients.

Access to either an ultrasound or CT for initial testing was also key and the diagnostic efficacy of these scans was influenced by the ability of radiologists to accurately distinguish any damage or abnormal change in the tissue.

Most importantly, the review identified that if sarcoma is left undiagnosed, the patient may have a worse prognosis than if found earlier on, certifying the importance of this report and the need for a continued commitment to improve early diagnosis for sarcoma patients.

Consultation with the sarcoma community

Who and how we engaged

Sarcoma UK consulted on our recommendations between April and August 2020. This consisted of two rounds of video/telephone consultations with over 57 patients and clinicians, one online survey and 5 focus groups. Quotes from these participants have been used throughout the report.

- **Zoom/telephone interviews:** Video/telephone interview participants were recruited from respondents to the National Sarcoma Survey 2020 and those known to Sarcoma UK. 25 patients and family members took part and provided us information about their experience of diagnosis and how this could have been improved. 32 clinicians shared their expertise on best practice and their input on the tangibility of our recommendations in their line of work. The interviews were semi-structured and lasted between 30 and 80 minutes.
- **Online survey:** A survey was distributed to all the clinicians that we contacted in the earlier stages of the project. It ensured that all types of clinician who are directly targeted by the recommendations had a chance to feedback to ensure that the recommendations had a positive influence on sarcoma diagnosis.
- **Focus groups:** Focus group participants were recruited from those that we had spoken to in the initial zoom/telephone interviews. Patients and their family members were selected by the relevance of their experience and their passion to be involved in the project. We held five focus groups through Zoom. Four of those meetings were of our Patient Advisory Groups, which was made up of two sets of patients, with 5 and 6 participants respectively. There were 5 participants in a further group, which contained those who lead sarcoma support groups around the country. The patients and family members which took part had all been diagnosed and treated within the UK.

13. Wilson, R., Wartenberg, M. & Lecointe-Artzner, E. (2017). Sarcoma Patient Pathway Analysis And Recommendations For Service Development. [Online]. Available from: researchgate.net/publication/313652236_Sarcoma_Patient_Pathway_Analysis_And_Recommendations_For_Service_Development.

Recommendations

Education of Healthcare Professionals

Background

- Among healthcare professionals at the initial point of contact for sarcoma patients, there is a distinct lack of knowledge of the symptoms of sarcoma and the appropriate pathways.
- This is extremely concerning, as a lack of awareness often leads to misdiagnosis, symptoms being dismissed and/or a lack of thorough testing and imaging.
- It also means that patients are seeing healthcare professionals repeatedly with the same or worsening symptoms and still not getting closer to a correct diagnosis.
- GPs are often seen as the gateway to diagnosis and this is certainly the case with sarcoma, where they are most often the first point of contact for sarcoma patients. The National Sarcoma Survey found that 83% of sarcoma patients initially went to their GP. However, the misidentification of symptoms is still common, with one study finding that symptoms were incorrectly interpreted by GPs for around 28% of sarcoma patients and the wrong advice was given to them accordingly.¹⁴
- Although sarcoma is a less common cancer, with 5,300 people diagnosed each year, a GP practice could expect to see a new case every 2 years.
- As physiotherapists rapidly become the first point of contact for a number of sarcoma patients,¹⁵ it is vital they are trained to identify the signs and symptoms of sarcoma, which are often initially identified as musculoskeletal.
- It is also unfortunately common among healthcare professionals to not consider sarcoma as a possibility due to a patient's young age. Anecdotally, we have heard from numerous patients about how their symptoms have not been seen as red flags and been dismissed as growing pains, a sports injury or psychological.
- The National Sarcoma Survey 2020 shows how both children and teenagers/young adults (up to 24), had a higher number of visits to a healthcare professional before they were diagnosed compared to adults. In fact, around half of children (48%) and teenagers/young adults (57%) visited a healthcare professional 3 or more times, compared to only a third (35%) of adults.

17%

of sarcoma patients are started on a treatment for another condition.

22%

are told their symptoms were not serious at their initial appointment.

15%

of patients had to see a healthcare professional more than five times before they were referred for further tests.

14. Younger, E., Husson, O., Bennister, L., Whelan, J., Wilson, R., Roast, A., Jones, R.L. & van der Graaf, W.T. (2018). Age-related sarcoma patient experience: results from a national survey in England. BMC cancer. [Online]. 18 (1). pp. 991. Available from: ncbi.nlm.nih.gov/pubmed/30333006.

15. First Contact Practitioner (2019). First Contact Practitioner-Home. Available from: firstcontactpractitioner.org.uk

Alyssa's story



“...it's essential that healthcare professions know more about sarcoma, so they can pick up symptoms that ring alarm bells more quickly.”

Katie's daughter, Alyssa, was 6-years-old when she was diagnosed with orbital rhabdomyosarcoma in August 2018. Katie tells the story of how her daughter was dismissed by multiple healthcare professionals even though her symptoms were visible and serious:

'My daughter woke up in the morning with a sudden onset of swelling and a droopy left eye. I immediately took her to our local hospital and they completely dismissed that there was anything wrong with my little girl. I then took her to see an optician who also dismissed all of my concerns.

Luckily, the next day I travelled to our local children's hospital and the experience was much better. They carried out the appropriate investigations and they quickly found the tumour behind my daughter's left eye.

I feel so passionate about telling my daughter's story, and about how utterly traumatising it was not to have a medical professional listen to your concerns as a frightened parent when your child obviously has a serious problem.

That's why it's essential that healthcare professions know more about sarcoma, so they can pick up symptoms that ring alarm bells more quickly. For my daughter, her symptoms could have been related to an eye infection, but it was something far more serious. Just by having sarcoma on their radar, it is likely they

would have been less dismissive and sent my daughter for a scan which would have shown the tumour.

My daughter had serious symptoms but had me to fight her corner. My worry is, if other children or adults don't have that same fight, or milder less obvious symptoms, they might go on living with a growing sarcoma for years.'

Last year, Alyssa ran a Race for Life after finishing her treatment and Katie went on to complete the Great North Run for Sarcoma UK.

“Neither of the GPs I saw knew what sarcoma was. However, my second GP was open to considering a different diagnosis. This attitude meant I was referred and my sarcoma was spotted.”

Ben Willett

What did our patient community say?

The more healthcare professionals that learn about sarcoma, or who choose to consider an uncommon diagnosis, the more sarcomas that will be diagnosed early.

Our patient community is extremely passionate about raising awareness among healthcare professionals, particularly for those who are in primary care.

There is a consensus among patients that the GP was the first point of contact for most sarcoma cases and that it was vital that GPs were equipped with as much information as possible about sarcoma.

Our community is also acutely aware of the number of illnesses which GPs see and were clear that they were not expecting them to have all the answers, but to refer them onwards or send them for further testing.

Physiotherapists were also identified as important professionals to be educated on sarcoma as so many people with sarcoma are referred to them for supposed sporting injuries and muscle pain.

The misinterpretation of scan findings made patients feel that training sonographers and radiologists should be a priority. A number of patients had their GP send them for a scan, but many found that the report from the scan said there was no concern, leaving them back at square one with no onward action for their symptoms.

Patients found that there was resistance to looking for a less common diagnosis. Even if a healthcare professional had exhausted all routes for their current diagnosis, they still seemed reluctant to send patients for scans or to consider other explanations.

They also highlighted the importance of primary care awareness around the heterogeneity of symptoms of sarcoma. As it can present as a lump, this is often the focus, but there are many other symptoms which can be associated with sarcoma, such as pain in a limb that is persistent when not using the limb.

Patients who had a long route to diagnosis found that there was no continual management of their symptoms by their GPs. Although many identified increasing lump sizes and pain, this was not considered even when they returned to the practice multiple times.

Overall, our community identified a clear lack of connection made between their symptoms and sarcoma amongst a number of healthcare professionals, spanning both primary and secondary care.

Lauren's story



“I need to share my Dad's story to get this message out there, as even if only one clinician that saw my Dad along his journey to diagnosis had thought about the possibility of sarcoma, they might have saved his life.”

Lauren's dad, Terry, was diagnosed with clear cell sarcoma in April 2019, at the age of 47. There was less than two months between his diagnosis and him passing away. Lauren talks about how he was misdiagnosed numerous times, leading to an eventual diagnosis that came too late.

'In September 2018, Dad started to experience pain in his knee. A blood test at the GP came back clear and he was told he had pulled a ligament and that it should sort itself out. Towards the end of 2018, he started to get a swelling/lump on the same knee along with the pain. A visit to the private hospital in January 2019 came back with the view it was a sports injury.

He then managed to get an ultrasound, followed by another GP visit for a new lump near his groin, which was also dismissed. He was referred on for physiotherapy, but in the meantime, the lump continued to grow and he was struggling to walk and drive. A further trip to the GP led to a referral to London's University College Hospital for a biopsy in late March, but he was still told it was not that serious.

He was finally diagnosed with sarcoma on April 8th, 6 months after his initial appointment. He then had more scans and his doctor told him that the cancer had spread from his knee to his chest, to his lymph nodes and his liver and on April 12th he was told it was terminal.

On June 4th 2019, he passed away. He was 47-years-old when he passed, was fit and healthy, didn't drink, never smoked, and until his cancer happened, he played football once a week. It only went to show that cancer can really happen to anyone.

I know that I need to share my Dad's story to get this message out there, as even if only one clinician that saw my Dad along his journey to diagnosis had thought about the possibility of sarcoma, they might have saved his life'.

Recommendation 1.

A sarcoma education programme for healthcare professionals should be rolled out, placing importance on the individual impact of sarcoma and how it is important to rule it out, not rule it in.

a. Funding and support are needed from Health Education England and the UK's health education bodies to work with healthcare professionals and charities to launch a learning programme in order to improve clinical knowledge and awareness of sarcoma and how to manage unexplained clinical features.

i. Provide free access to online resources for healthcare professionals, preferably as part of their accredited continual professional development (CPD), to learn more about the red flag features of sarcoma as opposed to a benign mass.

An accessible platform for GP and primary care nurse training would be used to host a blended learning module about sarcoma through funding from NHS. This would count towards clinicians' CPD making sarcoma a part of their ongoing learning. This module could be rolled out to other healthcare professionals which come into contact with sarcoma at diagnosis, such as those who work primarily in the Emergency Department.

Professional bodies representing healthcare professionals, primarily physiotherapists radiologists, radiographers and sonographers, should host a blended learning module about or featuring sarcoma. This learning should then be rolled out to other Allied

Healthcare Professionals and doctors/nurses in specialities that are more likely to come across sarcoma.

The NHS should provide the appropriate funding to make existing, and develop new, resources for musculoskeletal (MSK) radiologists to learn more about sarcoma, widening their skill set.

Altogether these online resources should focus on raising awareness of red flag symptoms of sarcoma, identifying the differences between lipomas and sarcomas, as well as embedding the appropriate investigation practices for unexplained clinical features.

ii. In association with the accredited courses, each specialist centre should allow specialists to use their training allowance to educate non-specialist physicians about the signs and symptoms of sarcoma.

This would allow the transfer of practical knowledge within healthcare professions, for those working at all stages of diagnosis. This could be achieved by:

- Implementing a programme of training days for triage centres to improve their ability to spot sarcoma, through both the non-symptom specific route and a lumps and bumps-specific pathway (if implemented). This would focus on educating sonographers, radiologists and pathologists who would be involved in the diagnostic work up.
- Give specialist clinicians the ability to organise training with local teams, such as GP networks, community

AHPs, local hospitals and community sonographers and radiologists.

- Improve GP representation on Sarcoma Advisory Groups (SAG) across the country. This could be informal and through Cancer Leads but would ensure that GPs in the area were aware of the most up to date issues and information on sarcoma.
- Implement a quality circle to ensure that those involved in diagnostic work are continually identifying and reviewing real sarcoma cases, so referring clinicians are assured that they continue to have the relevant expertise.

b. Medical programmes should include awareness of rare cancers as part of formal medical training across all specialities.

This should be featured in both undergraduate and postgraduate education.

- Undergraduate education should aim to make students aware of sarcoma and provide them with basic learning.
- Postgraduate education should aim to provide students with tailored education which would focus on how sarcoma interacts with their specialism, making them aware of the key differences between a benign mass and sarcoma and encouraging comprehensive investigations with red flag or unexplained symptoms.



A successful model at Nottingham University offers physiotherapy students a surprise teaching week, where they assess unknown scenarios initially and then learn about sarcoma through teaching by a specialist, practical sessions and speaking to patients about their experience.

c. Cancer Alliance Primary Care Clinical Leads should ensure that primary care professionals have knowledge of local pathways for sarcoma and have clear information on how it is diagnosed.

Commissioning groups should work together to ensure that Primary Care Leads have access to, and distribute information on, the referral pathway from their specialist centres. They should also distribute an accessible document or video for primary care professionals to improve their knowledge of sarcoma.

Through this distribution of information primary care professionals need to be aware of:

- The specificity of sarcoma symptoms and where they differ from other illnesses where sarcoma is commonly misdiagnosed. e.g. the deep persisting pain for a bone sarcoma is often not related directly to activity (but could often wake you up at night), feeling you are full with a gastrointestinal stromal tumour (GIST), soft tissue sarcoma (STS) does not have to be painful.
- The importance of continual management of a lump that the primary care professional does not believe fits the current criteria for concern. It is the responsibility of the GP to make the patient aware of any necessary check-ups and what signs/symptoms would require a further appointment.
- The need for adequate clinical information on referral to ensure that the action resulting from scans/tests or a decision on treatment can be fully informed. When

referring patients onwards a submission of clinical information and comorbidities should be mandatory.

- Their ability to contact a specialist centre or clinician to confirm the next steps where they are unsure whether to refer for suspected sarcoma or they think a patient may need an urgent referral.
- Much of this information already exists through the work of patient-supporting charities, but distribution and education is key.

d. The NHS needs to ensure that primary care professionals are considering a differential diagnosis when diagnosing patients with more common conditions.

The NHS should encourage healthcare professionals to consider the vague symptoms pathway when more common conditions relating to the patient's symptoms are unlikely or unresolved by treatment. Information provided to healthcare professionals on common conditions such as cysts or growing pains, and vague symptoms such as tiredness/lethargy and abdominal pain, should indicate the possibility of cancer and encourage healthcare professionals to use the vague symptoms pathway where they do not have an informed diagnosis.



- Identifying red flags is key in accelerating sarcoma diagnosis, and in reducing the chances of patients receiving treatment for another condition, or causing irreversible damage.
- The Royal College of Obstetricians and Gynaecologists (RCOG) have recently introduced consent advice which now includes a list of red flags for gynaecological sarcoma.¹⁶ This ensures both patients and healthcare professionals are aware of the signs of potential uterine sarcoma and comprehensive checks are met to try to rule this out.
- The RCOG should look to ensure that this practice is being followed and to help meet their long term early diagnosis goals. Others should seek that a red flag checklist prior to treatment is created by specialties where misdiagnosis of cancer is common.

16. Royal College of Obstetricians and Gynaecologists (2019), Morcellation for myomectomy or hysterectomy (Consent Advice No. 13). Available from: [rcog.org.uk/en/guidelines-research-services/guidelines/consent-advice-13/](https://www.rcog.org.uk/en/guidelines-research-services/guidelines/consent-advice-13/).

“Identifying red flags is key in accelerating sarcoma diagnosis, and in reducing the chances of patients receiving treatment for another condition, or causing irreversible damage. ”

Public Awareness

Background

- Public awareness of sarcoma and its symptoms is unfortunately very low. Improving this is essential as it means an individual is more likely to recognise their symptoms, go to a GP to have them checked out, and increase the chances of them being diagnosed faster.
- Comparably, more common cancers are widely recognised by the public. For example, in a Cancer Research UK study, 94.9% of those surveyed identified breast cancer as one of the top three most common cancers and a further 88% were also aware of its screening programme.¹⁷
- The National Sarcoma Survey 2020 also demonstrated that patients were taking a long time after having symptoms to make an appointment with a primary care professional, with 43% of participants (16+) waiting more than 4 weeks, compared to 17% in breast cancer patients who presented after a month.¹⁸
- Although this wait may be dependent on a number of factors, this clearly demonstrates that we need to improve awareness of sarcoma symptoms and the confidence of the public to present these symptoms to their GP.
- On balance, although there is a lack of available literature on sarcoma awareness, the information which we do have strongly points to the need for consistent and regular awareness-raising campaigns about symptoms, empowering people to seek medical advice and providing positive information about the value of early education.

17. Cancer Research UK (2009). Public awareness of cancer in Britain. Available from: cancerresearchuk.org/sites/default/files/public_awareness_of_cancer_in_britain_dh_report.pdf.

18. Figures from a YouGov Plc survey for Breast Cancer Care unless otherwise stated. Fieldwork was undertaken between 11-16 February 2015 online. Total sample size 409 people, including 403 women.

What did our patient community say?

- Our patient community have been extremely vocal about how important public awareness is to them. Better public awareness would not only make having sarcoma feel less isolating but knowing the symptoms could potentially save someone's life.
- They have spoken to us about how a lack of awareness meant they put off seeing a GP as they did not connect a lump or swelling on their limbs to cancer. However, this is something they would have done for a lump in their breast or on their testicles.
- They have also identified how it can often be difficult to try to talk about having sarcoma with family, friends or others, when they are unaware of what sarcoma is and that it is a cancer.

“We need to get the message out to anyone and everyone – the more people who are aware of sarcoma, the more people who will be diagnosed before it is too late.”

**Charlotte Beckerleg,
member of Patient Advisory Group**

75%

of the public said they did not know what sarcoma was and even among people who had heard of sarcoma.

29%

of the general public who felt they knew what sarcoma was, still had no idea what the symptoms were.

Uma Paul's story



“I never knew anything about sarcoma before I was diagnosed so it is really important to me to build awareness. It took me 6 years to be diagnosed.”

Uma's 6-year journey to diagnosis started when she was just 11 years old. She started having pain around her knee and was continually misdiagnosed, being told by multiple healthcare professionals that her lump was a cyst or the pain was psychological.

Uma is now at university and continues to spread awareness of sarcoma by doing talks to fellow students about her experience. She also reflects on why she continues to spread awareness:

“I never knew anything about sarcoma before I was diagnosed so it is really important to me to build awareness. It took me 6 years to be diagnosed. When I was 15 or 16, I was going to the doctors every week and still no-one knew what was wrong or that it could have been sarcoma. However, the more awareness there is, the more people that can look out for signs and symptoms for themselves and others.”



Recommendation 2.

We need to raise awareness of sarcoma and its symptoms. Sarcoma can occur anywhere in the body and it is vital that the public are aware of this.

a. Representative public health bodies should run or collaborate on ongoing campaigns to spread awareness of sarcoma and or the misidentification of its symptoms.

The public need to be aware of the symptoms of sarcoma so they know when to seek an appointment with a healthcare professional.

It is also important to tackle common misconceptions about the location of cancer in the body and who cancer affects. This would empower patients to visit their GP, knowing that they need to get their symptoms checked out as soon as possible. Two key messages to overcome these misconceptions are:

- **Sarcoma cancer is rare but it can occur everywhere.**

The public need to be aware that cancer is not only site-specific, such as in the breast or the prostate, but can be found anywhere in the body. This knowledge will encourage patients to visit a healthcare professional when they identify a lump or swelling anywhere on the body and know they

have reason to get it fully checked out; this could take months or years off a patient's diagnosis.

- **Sarcoma affects people of all ages, including young children and adults.** There is a common misconception that cancer rarely occurs in fit and young people. This results in younger people waiting longer to get their symptoms checked out. For example, we found that 25% of 16-to-25-year olds were waiting more than a year to visit a healthcare professional when they first have symptoms. This gives a large window for symptoms to progress and for the tumour to get bigger, worsening outcomes.

b. Department of Health and Social Care should fund and pilot an interactive wellbeing initiative that encourages its colleagues to check for symptoms of all cancers.

This initiative would encourage individuals to improve their knowledge on symptoms of rarer cancers to make them more confident to visit their GP if they are concerned.

- This would add to existing wellbeing initiatives, such as those that focus on mindfulness or mental health, to demonstrate the importance of colleagues taking care of their physical health.
- The initiative would deliver colleagues essential information about lesser-known symptoms of cancer and the key messages that cancer can be found anywhere and can affect people of all ages. This could improve the public's knowledge of when to visit a healthcare professional, reducing the delay in presentation.
- If the pilot scheme was successful, this scheme could be scaled up and pitched to both private and public sector companies as part of their own wellbeing initiatives and used for a learning session in secondary schools.

“75% of the public said they did not know what sarcoma was”

c. Representative public health bodies to provide a grant to improve public awareness of rare cancers and increase distribution of resources.

- A grant would demonstrate the importance of the early diagnosis of rarer cancers, and provide rare cancer charities the resources to scale up their campaigning, to have a wider reach and more leverage in the wider public domain, as is the case with common cancers.
- A grant could fund a Rare Cancer Awareness Initiative, set up a GP and patient communication campaign or work with external online websites to connect symptom searches with sarcoma.

Effective and Efficient Sarcoma Referrals and Scans

Background

- Issues in diagnosis can occur after a primary healthcare professional believes that symptoms warrant further investigation.
- Diagnostic efficacy is influenced by the ability of the healthcare professional overseeing and reporting on the scans to accurately distinguish the lesions. Although, the British Sarcoma Group (BSG) guidelines are clear that a clinician with Fellowship of Royal College of Radiologists or Royal College of Radiologists accreditation should perform and report ultrasound (preferably musculoskeletal ultrasound),¹⁹ patients have told us this is commonly not the case.
- There is also a lack of knowledge among primary healthcare professionals of the correct referral pathway. It is not uncommon that GPs are referring via incorrect specialists, giving these patients a further delayed diagnosis.²⁰
- Adherence to the BSG guidelines for onward referral was also low – as soon as sarcoma is suspected, the patient should be sent to a sarcoma specialist centre (as specified in the British Sarcoma Group- UK guidelines for the management of soft tissue sarcoma/ bone sarcoma).²¹
- A study at the Royal Orthopaedic Hospital (Birmingham) demonstrated that out of 88% of patients who had at least one of the guideline features of suspected sarcoma, only 11.3% of patients were referred within 1 month, while 32.7% of patients took longer than a year.²²
- The establishment of clear referral pathways would enhance access to expert diagnosis and treatment for sarcoma.²³
- Both the delay in sending patients for imaging and the failure to refer patients to a sarcoma specialist centre can worsen a patient's prognosis and prevent them from receiving the best possible outcome.

19. British Sarcoma Group (2019). Ultrasound screening of soft tissue masses in the trunk and extremity. Available from: britishsarcomagroup.org.uk/wp-content/uploads/2019/01/BSG-guidance-for-ultrasound-screening-of-soft-tissue-masses-in-the-trunk-and-extremity-FINAL-Jan-2019.pdf.

20. Johnson, G.D., Smith, G., Dramis, A. & Grimer, R.J. (2008). Delays in referral of soft tissue sarcomas. *Sarcoma*. [Online]. 2008. pp. 378574. Available from: ncbi.nlm.nih.gov/pubmed/18317511.

21. Dangoor, A., Seddon, B., Gerrand, C. et al. UK guidelines for the management of soft tissue sarcomas. *Clin Sarcoma Res* 6, 20 (2016). doi.org/10.1186/s13569-016-0060-4.

Gerrand, C., Athanasou, N., Brennan, B. et al. UK guidelines for the management of bone sarcomas. *Clin Sarcoma Res* 6, 7 (2016). doi.org/10.1186/s13569-016-0047-1.

22. Johnson, G.D., Smith, G., Dramis, A. & Grimer, R.J. (2008). Delays in referral of soft tissue sarcomas. *Sarcoma*. [Online]. 2008. pp. 378574. Available from: ncbi.nlm.nih.gov/pubmed/18317511.

23. Wilson, R., Wartenberg, M. & Lecointe-Artzner, E. (2017). Sarcoma Patient Pathway Analysis And Recommendations For Service Development. [Online]. Available from: researchgate.net/publication/313652236_Sarcoma_Patient_Pathway_Analysis_And_Recommendations_For_Service_Development.

What did the patient community say?

- Our patient community were extremely concerned about imaging they received and clinicians' hesitation to refer them for further tests.
- A number of our patients had their ultrasounds done locally or by experts without adequate training and as a result their sarcoma was missed.
- A vast number of patients experienced delays in their diagnosis when their scans and/or reports were not made available to other clinicians looking at their case. Initial findings are often overridden when viewed by an appropriate specialist, and sadly previous clinicians in the chain may not carry out the appropriate or any further investigation.
- Patients also felt that there was a lack of expertise by those carrying out the scans. Features indicative of cancerous tumours were not identified by sonographers as needing further investigation. This demonstrated that without oversight of an expert, sarcoma is being missed, even with a scan.
- Patients also identified gaps where reports were not routinely sent to a radiologist for review, particularly when findings were inconclusive.
- Primary care professionals were often not aware of the red flags of sarcoma when reading the imaging. Once they had seen a scan, many GPs took no action to follow up any matters of concern.

“You could see on the scan that my tumour had a blood supply but still no-one identified it as sarcoma.”

**Marie Halford,
member of Patient Advisory Group**

Sue Mutch's story



“Throughout, I had seen at least five doctors and loads of nurses, but the clinical decision always seemed to rest on that original scan, which none of them had seen.”

Sue, who is 64, was diagnosed with synovial sarcoma five years ago, she talks about her experience of diagnosis and how one non-expert scan report led to her sarcoma being operated on as a cyst:

‘I initially went to the GP with a small lump on my left foot, which was dismissed, even when it continued to increase in size. After six months I was finally sent for an x-ray, but that they did not see anything on the scan. I was then sent for an ultrasound and was told I had a ganglion cyst. Neither myself or the doctor saw the report or the scan but this was confirmed by an external scanning company.

About a year later, I was walking differently and in pain so went back to my doctor. They tried to drain the ‘cyst’ but hardly any fluid came out, so they said that I would have to have an operation to remove it. They could not see the scan or the report from the external company but used their evaluation to decide upon surgery.

I delayed the operation for 6 months to have my hip replacement, which I was told was the priority. But when I finally had my operation, it was not until a fortnight after and my stitches were being removed that they told me it was sarcoma.

After being referred to the sarcoma specialist team I had to have another surgery as they hadn’t removed enough of the area of the tumour in my foot.

Throughout this time, I had seen at least 5 doctors and loads of nurses, but the clinical decision always seemed to rest on that original scan, which none of them had seen. This was very frustrating, as looking back, if they had done another internal scan which all these doctors could have seen, it is more than likely one of them would have identified the tumour, preventing me from having to have an extra surgery and so I could have prioritised my sarcoma surgery when the lump was much smaller.

I want to share my experience to highlight the importance of getting a quick and accurate scan, which is both accessible and has had oversight from a trained radiologist.’

Recommendation 3.

Ensure that there are clear and efficient referral pathways that allow primary healthcare professionals to access the optimum route for all their patients.

a. As part of their commitment to improve early diagnosis, the NHS should improve quick access to scans and standardise the quality of reporting.

i. The NHS should ensure that progress is being made on their £200 million commitment to improve cancer diagnostics, which should include improving access to MRI and ultrasound.

This commitment should look to include:

- Uniform access to two-week ultrasound diagnostics for all primary healthcare professionals, within their region.
- Improving access to imaging and reports, making them available to all clinicians in the onward chain of treatment.

ii. NHS should set up a red flag pathway to run through triage centres. Where possible, this should be rolled out through a triage centre model across the UK, building on the non-specific symptom pathway. This should allow primary care professionals to access rapid diagnostics, through two pathways, a sarcoma specialist centre or triage centre.

- A uniform red flag pathway would allow primary care professionals to send patients who have a specified red flag symptom, such as an increasing size of lump or swelling to a triage centre for imaging review by an expert, without having to determine what type of tumour it is. This would ensure that those who are not sent through the 2-week wait have another pathway which will give them a quick diagnosis.
- Triage centres with a red flag pathway would carry out imaging with the oversight of a trained radiologist who reviews cases of suspected sarcoma and is within – or has a direct link with – a sarcoma centre. Expert oversight would prevent scans and reports from being read inaccurately, and would allow a triage to take place patients with benign tumours not requiring to go to a specialist centre.
- Where a triage centre is within a Rapid Diagnostic Centre, these will eventually have a sarcoma-specific two week wait pathway too, creating a specialised regional hub for sarcoma diagnosis.
- One-stop' clinics would give sarcoma specialist centres the capacity to be able to complete as much of the diagnostics as possible in one visit. Ultrasound and biopsy (and where necessary, MRI) could take place on the same day. Where this is not possible, these clinics could be used to ensure patients have appointments booked in ready for follow up testing or treatment.
- Where the linked sarcoma specialist centre believes a diagnostic centre is capable of local MRI and biopsy this could take place prior to referral to a specialist centre.

iii. The NHS should standardise synoptic reports and build frameworks where radiologists and sonographers are able to take ownership of the action resulting from the scan.

- This standardisation would ensure that the report contained the suggested next steps (e.g. referral to a specialist centre, to rescan 6 months later to check the tumour) if returned to a GP and to be able to request or directly gain full clinical information (minimum dataset) to make their evaluation for onward referral. This would allow specialists to be informed of the full diagnostic pathway and ensure they can discuss the case appropriately before their first patient consultation.
- It could also require that reports have a front sheet which is given to patients to explain the results of the scan and any further action which they need to take. This would empower the patient and give them control in ensuring that their condition is successfully monitored.

How could this work?

Having spoken to specialist clinicians across the UK, many regional complexities and differences emerged in terms of how sarcoma centres operate. There are a number of factors that affect how triaging patients will vary, such as size of catchment areas and the numbers and expertise of clinicians (both, within centres and all hospitals/surgeries that report to that sarcoma centre).

The purpose of this section of the recommendation is to streamline referral pathways to allow patients to get a diagnosis as quickly as possible, and for specialist centres to be able to provide the best treatment possible for sarcoma patients. Therefore, the triage of patients may take on different models but with the overall aim that they allow patients to get a rapid diagnosis.



Mr Dirk Strauss, Consultant Surgeon, and Dr John Bush, Consultant Musculoskeletal Radiologist, talk about how they have been part of the successful partnership between Brighton and the Royal Marsden. Brighton runs a clinic that triages suspected sarcoma patients:

'Before the existence of local diagnostic centres, many patients from as far as Chichester and Eastbourne had to travel to be seen in London for diagnostic scans for any suspicious soft tissue lump and bump. We were having to focus on an increasing number of urgent referrals, which was utilising significant clinic and imaging slots, while the diagnosis of sarcoma was very low (+/-5%). Patients often had to make several trips to attend clinics, and have scans or biopsies with the associated anxiety of being referred to a cancer hospital.

We now have a number of dedicated local diagnostic centres that feed into us, which includes the Sussex Soft Tissue Sarcoma Diagnostic Unit in Brighton. This model allows patients who are in closer proximity to Brighton to be sent to a dedicated diagnostic clinic for imaging and testing of their lumps and bumps. This means that the 95% of patients who will not have sarcoma can be seen quickly and locally, and as a specialist centre we have been able to focus on diagnosing and treating patients with sarcoma.

What works so well with this model is that we have a close relationship with the clinicians who run the local diagnostic clinic. When they see a patient with concerning features from their initial ultrasound they can let us know so we can see the patient as quickly as possible. Similarly, if there is a case which they are unsure about they can refer it to our sarcoma MDT for review of locally performed imaging and biopsies and recommend onward management. I already know I will receive referrals after their local MDT on a Thursday and I am usually able to get these patients seen at the Royal Marsden Hospital within a week.

Having the local diagnostic centres means that patients can have their diagnostic work up done more efficiently. The team of knowledgeable clinicians at the local centre are aware of how to identify sarcoma and are able to speak to us at the sarcoma centre at any time. By having this pathway, it can hopefully reduce the numbers of patients who are sent for poor quality ultrasound and are getting unnecessary inconclusive findings.'

Mr Dirk Strauss, Consultant Surgeon, The Royal Marsden NHS Foundation Trust

"What works so well with this model is that we have a close relationship with the clinicians who run the local diagnostic clinic. "

Mr Dirk Strauss

“...as such the patient journey from referral, through diagnosis to treatment is much quicker and more efficient for patients.”

Dr John Bush

We started our radiologist-led diagnostic unit in 2011. Our most important aim was to facilitate the early diagnosis for patients with soft tissue sarcoma.

Historically, patients with soft tissue sarcomas have been difficult to diagnose because they are rare, and are often slow growing tumours, and therefore may be mistaken for benign diagnoses for many months or years. Paradoxically, the vast majority of soft tissue lumps and bumps are benign, and patients can then undergo unnecessary investigation, which can be very distressing for them. Another key aim then was to manage all soft tissue lumps and bumps appropriately, efficiently and empathetically.

We have been able to do this by working as a team within the Imaging Department and by working closely with our Pathology Department at Brighton and Sussex University Hospitals NHS Trust, and through the excellent support and guidance we receive from the Royal Marsden Hospital.

We are also indebted to our local diagnostic unit service co-ordinator, who along with five Consultant Musculoskeletal Radiologists, Musculoskeletal Sonographers, and Specialist Registrars, is a key member of our team, as are our local GPs, who we rely on to relay key clinical information during their patient's journey through our service, and our pathologists who analyse the image guided biopsies we perform.

We see many patients each year, in excess of a thousand patients currently, with a vast array of diagnoses, ranging from patients with high grade soft tissue sarcomas, lymphoma and metastases, through to patients with benign lipomata and ganglion cysts.

The success of our service is down to excellent team working within our imaging department which means growing and sharing knowledge about suspected soft tissue malignancy within the team, and the unfailing support of the Royal Marsden Hospital when necessary.

All the diagnostic work-up, including image guided biopsy is performed locally which means our patients are not travelling long distances unnecessarily. Because the Royal Marsden has invested their time in supporting us, over time, our referrals to them for advice and further imaging review have decreased exponentially, as such the patient journey from referral, through diagnosis to treatment is much quicker and more efficient for patients, primary care, local hospital and tertiary referral centre.

For any hospitals contemplating offering a similar service, I think a team approach between the Imaging and Pathology Departments and excellent communication with the tertiary centre is essential.

**Dr John Bush, Consultant Musculoskeletal Radiologist,
Brighton and Sussex University Hospitals NHS Trust**

Route to diagnosis – North of England Bone and Soft Tissue Service



■ Sarcoma pathway

■ Action by the sarcoma specialist team

■ Action outside the sarcoma specialist team

“We have been able to provide a one stop service for a lot of our patients whereby our patients can meet their consultant, have an ultrasound/biopsy, possibly an MRI, all in one day.”

Karen Fisher

Karen Fisher, Clinical Nurse Specialist, explains how the Newcastle Upon Tyne Hospitals NHS Foundation Trust is effectively ensuring that sarcoma patients are diagnosed as quickly as possible:

‘In Newcastle we have a choose and book system whereby referrals can be sent in as a 2 week wait or non-urgent. These can be down or upgraded appropriately by the consultant triaging. We also have an email advice service whereby the GPs can seek guidance if they are unsure about a case and the need to refer. A GP is part of our sarcoma advice group which meets twice a year. We also get internal referrals via email which are also reviewed by the consultant.

We have provided awareness days to sonographers and radiologists within our region. This was successful and gave off-site sonographers and radiologist’s further awareness of some of the trigger points to highlight a suspicious lesion and where they may need to refer to a specialist centre.

We have been able to provide a one stop service for a lot of our patients whereby our patients can meet their consultant, have an ultrasound/biopsy, possibly an MRI, all in one day. Also, we have a facility of having pre-assessment slots allocated to the service on the same day which we can utilise should we need to get the patient to surgery quickly. This is to prevent multiple trips to the hospital and try to make the sarcoma pathway as smooth and efficient as possible’

Karen Fisher, Clinical Nurse Specialist, The Newcastle Upon Tyne Hospitals NHS Foundation Trust.

b. Cancer Alliances should ensure that there is a clear communication pathway for healthcare professionals throughout the diagnosis journey.

- Cancer Alliances would make the contact information of the lead doctor at both the sarcoma specialist centres and Rapid Diagnostic Hubs available to primary care professionals, to allow for any necessary follow up and for effective feedback to improve quality of referrals.
 - Each Cancer Alliance would have either a personal or central line to allow primary care to make contact with a specialist centre where they have concern about a patient or are unsure of onward action.
-

c. Review the guidelines for referral ensuring that they have the appropriate input from sarcoma specialists and monitor the adherence to these guidelines to ensure that they are effective.

- Across the UK there are a number of different guidelines which give clinicians advice of how to identify and refer sarcoma.
- The National Institute for Health and Care Excellence (NICE) regulates this advice in England and is often drawn upon by other nations to develop their guidance. In Scotland, sarcoma referral is covered by the Scottish Guidelines for suspected cancer, in Northern Ireland, clinicians can refer to the Northern Ireland Referral Guidance for Suspected Cancer – Red Flag Criteria and in Wales, the Directory of Cancer Services, NHS Wales provide this information.
- NICE Guidelines for suspected cancer: referral and recognition (2015) should be reviewed by sarcoma clinical specialists and patients and be updated to include further detail on when and where it is appropriate to refer patients. It should try to ensure that is prescriptive of the red flag symptoms, particularly of GIST (abdominal pain and bleeding) which presents differently to common STS symptoms.
- NICE Guidelines for Improving Outcomes for people with sarcoma (2006) should be reviewed and updated through an evidence-based approach to ensure that any changes are robust and are fully incorporated into practice.
- The NHS should ensure that their quality standards adequately monitor the application of the Sarcoma Service Specification in each specialist centre and the wider community, where applicable, to ensure there is compliance.

Next Steps

What we can do as Sarcoma UK

Early Diagnosis Steering Group

The recommendations in this report address the avenues which we will influence externally, but we also identified a wealth of opportunities which we could lead on, both as Sarcoma UK alone, and in collaboration with other charities.

To guide this work, we will set up an Early Diagnosis Steering Group of advocates from across the sarcoma community, who will monitor our progress and help us implement aspects of our early diagnosis work.

The Steering Group, alongside our other supporters, will play a leading role in taking this work forward. Some ideas which we will look to explore further with this group are:

- Creating an interactive Sarcoma Education Programme. Develop a patient-led initiative where those affected by sarcoma can speak to GPs about their story or develop video case studies to deliver in training.
- Creating specialist leads to promote early diagnosis within their sector. Specialists will represent Sarcoma UK at conferences and events, where they can talk about sarcoma specifically and within the wider narrative.
- Continuing to raise public awareness through or communications and social media channels. Take opportunities to expand our network and try to increase general awareness of sarcoma and its symptoms.
- Working closely with cancer charities to form a louder voice on early diagnosis. Working together with charities who have a common goal to ensure that both healthcare professional and public awareness work reaches as wide an audience as possible.

What we will do to influence externally

Work with the public and professional bodies targeted in our recommendations to ensure that they consider the concerns that have been raised, and so we can develop a collaborative solution going forward.

Work with Parliamentarians and civil servants across all four nations to promote this early diagnosis work and influence political action going forward.

Key themes not covered by the recommendations

Research into Early Diagnosis

Through the course of this project, a strong case emerged around the role of better quality data and further research to improve diagnosis. A number of promising avenues have been explored, such as into the use of AI to interpret scans, which could help to improve diagnostic efficacy.

Sarcoma UK would welcome more research into this area, both within our own funding streams and those of other research funders. We will place a priority on research that aims to reduce the time to diagnosis for patients, either directly through developing new diagnostic methods or markers, or indirectly through optimising the diagnostic pathway and patient experience.

Psychological Support at diagnosis and beyond

Data from the National Sarcoma Survey was released in July 2020, with 90% of respondents reporting that the diagnosis and treatment of sarcoma negatively affected their overall mental health/emotional wellbeing and 40% saying they were not given enough emotional support by hospital staff.

We heard many powerful accounts from patients about cancer support services not being aware of sarcoma and not signposting them to any sources of support either within or outside the hospital.

As a result of these discussions, Sarcoma UK recently released our policy briefing, Psychological Impact, which details our three top priorities in this area: to encourage sarcoma specialist centres to offer ongoing mental health services; improve awareness and the role of healthcare professionals in providing support; and increase patient awareness of additional services.

This marks the beginning of Sarcoma UK's focus on psychological impact and we will actively be pursuing these priorities, in collaboration with our patient community, to ensure that we can improve the support available.

Report Summary

Summary of the findings

These recommendations outline the essential steps that policy makers need to take to improve the diagnostic landscape for sarcoma patients. Individually they could move the dial, making a real difference for sarcoma patients. And in combination, they have the possibility to deliver a true step-change in maximising diagnostic efficiency, helping patients and healthcare professionals to recognise symptoms earlier and improving the quality and interpretation of scanning.

These recommendations require action at all levels. At a national level, they call for the NHS and representative public health bodies to invest in public awareness and the value of shared learning and education. At a regional level, they need buy-in from each sarcoma centre to work with triaging units to ensure a smooth diagnostic pathway. Finally, at a local level, they require primary care clinicians to be willing to learn about sarcoma and consider the differential diagnosis.

At Sarcoma UK we also know that there is a lot more we can do to improve early diagnosis, and we will continue to work with patients and clinicians to achieve this result. We see this report as not just as a call to action for policy makers, but as a catalyst to bring people together to ultimately improve diagnosis and save lives.

Closing thoughts and thanks

Sarcoma UK would like to thank everyone who helped us to create this report.

- The clinicians who gave their time to have multiple video calls with us, and responded to our online survey to refine the final recommendations. With special thanks to Dr Christina Messiou, Mr Dirk Strauss, Dr John Bush, Karen Fisher, Dr Anant Desai.
- The patients and their families, who we had in-depth conversations with to learn about their experience, and fed back on our recommendations. With special thanks to all those patients who allowed us to share their stories in this report and our wider communications.
- MP Jess Phillips, who has shared her personal experience with sarcoma and has supported the release of this report.
- The charities and professional bodies, who allowed us to test our recommendations with them and who shared them with their wider networks.
- A special thanks to the members of the Patient Advisory Group, who provided us invaluable insight into their or a loved ones' sarcoma diagnosis, allowing us to ensure that these recommendations would positively impact on sarcoma patients and their families. Quotes of their journey are used throughout the report.

Members of the Patient Advisory Group

- Marie Halford
- Brian Simpson
- Ben Willett
- Roger Wilson
- Andrew Sutton
- Emma McCloskey
- Sue Mutch
- Karen Delin
- Charlotte Beckerleg
- Ceri Potter
- Linda McIlwrath

Glossary

AHPs – Allied health professionals are the third largest clinical workforce in the NHS. Made up of 14 unique and diverse professions, their practice is integral to most clinical pathways. They work across organisational boundaries, providing solution-focused, goalcentred care to support patients' independence.

RDCs – Rapid Diagnostic Centres (RDCs) are designed to speed up cancer diagnosis and support our ambitions to achieve earlier diagnosis, with improved patient experience, for all patients with cancer symptoms or suspicious results.

BSG – The British Sarcoma Group (BSG) is the association of the specialist clinicians, nurses and supporting professionals who treat patients with sarcoma in England, Wales, Scotland and Northern Ireland.

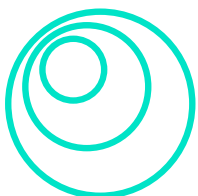
SAG – Sarcoma Advisory Groups facilitate the collaboration of providers of sarcoma services to provide optimum care based on best clinical practice.

Sarcoma Service Specification – The service specification (the "Specification") covers the provision of care for people with sarcoma cancer, including bone sarcoma, soft tissue sarcoma and gastrointestinal stromal sarcomas (GIST), in England.

Sarcoma Specialist Centre – The centre at which all patients diagnosed with a suspected soft tissue or bone sarcoma, should be referred to for final diagnosis and the management of their treatment. If diagnosed outside this centre it should still be under their direction.

STS – Soft-tissue sarcoma.

GIST – Gastrointestinal stromal tumour.



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