



# Tackling Sarcoma Together: Sarcoma UK's Strategy 2021-2026



**Sarcoma UK**  
The bone & soft tissue  
cancer charity

# Sarcoma UK

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

## Our vision

Where everyone affected by sarcoma cancer has the treatment, care and support they need.

## Our mission

To ensure everyone affected by sarcoma receives the best treatment, care, information and support available and to create the treatments of the future.

## Our values

### Community

We bring together everyone affected by, or with an interest in sarcoma into one strong, caring and mutually supportive sarcoma community. We are seen as a lifeline by many. We seek to inspire everyone in the sarcoma community to achieve our mission.

### Expertise

We use best practice in everything we do, ensuring that our work is accurate and informed by expert sources. We aspire to professional excellence to maximise impact.

### Dynamism

We are a young charity that seeks to transform the sarcoma community through a dynamic and flexible team ethic.

### Impact

We constantly monitor the impact of our work, making sure it meets the needs of our stakeholders and that our supporters' funds are used effectively.

## Creativity

We push boundaries and seek new and creative ways to deliver our work to maximise its impact.

## Partnership

We work collaboratively and in partnership with other organisations, healthcare professionals, scientists and researchers, both in the UK and overseas, to achieve our objectives.

## Integrity

We are transparent in our work, and put patients and their needs at the heart of everything we do.

# Introduction

As we enter our tenth anniversary year, this ambitious strategy sets out what we want to achieve over the next five years and beyond.

We have come a long way since 2011 when we formally became Sarcoma UK, and we've made great strides in making a difference to all those affected by sarcoma. However, we cannot afford to be complacent.

In developing our thinking behind the strategy, Sarcoma UK has had to be more agile and nimble in the face of challenging times. We need to be fit for the future and to focus our efforts where they will make the most difference for people affected by sarcoma. As a result, our aims have been shaped around what we have heard directly from the patients, family members, organisations and healthcare professionals who make up the sarcoma community.

While there are still many unknowns, one thing is certain. With your support, we can continue to build on the progress of our first decade. In delivering this strategy, we are truly advancing together towards a time when everyone affected by sarcoma has the treatment, care and support they need.



*Richard Davidson*

**Richard Davidson,  
Chief Executive**

# The story so far

The year 2021 will be the tenth anniversary of the year we formally became Sarcoma UK. This timeline pinpoints some of the key developments in our history.

## 2003

Roger Wilson and his wife Sheelagh started work on what would become Sarcoma UK from their home in Shropshire

First newsletter published with support from Pharmamar

Sarcoma UK registered as a company limited by guarantee

## 2005

The charity established a specialist GIST support group which ultimately became GIST Support UK

First open national British Sarcoma Group Conference, managed by Sarcoma UK

## 2007

First donations over £1,000 received – one through British athlete Richard Whitehead's marathon running

The Sarcoma Trust created to focus on research

National patient meeting held in Torquay

## 2009

A philanthropic donation of £250,000 helps drive the development and restructure of the charity

British Sarcoma Group publishes its first clinical guidance for soft tissue sarcoma

First research grants awarded – four projects with a total spend of £255,000 at the University of Sheffield, Royal Marsden Hospital and The Institute of Cancer Research

Sarcoma Patients Euronet (SPAEN) formed with Sarcoma UK as a founding member

## 2011

Sarcoma UK officially launched at an event with National Cancer Director, Professor Sir Mike Richards

Independent equity research firm The Analyst lends its support to Sarcoma UK

## 2004

First invitation meeting of British Sarcoma Group

Imatinib (Glivec) is the first sarcoma drug to be approved by NICE with input from Sarcoma UK

## 2006

NICE Improving Outcomes for People with Sarcoma document published with input from Sarcoma UK

First Support Group set up (online email group)

## 2008

First face to face Support Group set up

## 2010

NICE approves trabectedin (Yondelis) for soft tissue sarcoma and acknowledges the value of patient input through Sarcoma UK

Sarcoma UK relaunched and team established in London

Sarcoma UK produced first Patient Information packs for clinical teams to tailor for individual patients

|  |  |   |  |  |
|--|--|---|--|--|
| <p><b>2012</b></p> <p>Sarcoma UK launches pilot Golf Ball campaign in Birmingham, aimed at raising awareness of sarcoma among GPs and the public</p> <p>First National Sarcoma Forum meeting for sarcoma nurses and allied healthcare professionals held in Birmingham and supported by Sarcoma UK</p> | <p><b>2014</b></p> <p>Survey and report, <i>Hidden Cancer</i>, which focused on gynaecological sarcoma published</p> <p>Launch of the nationwide 'On the Ball' campaign targeting GPs</p> <p>First <i>Understanding Sarcoma: A new patients' guide</i> booklet published</p> | <p><b>2016</b></p> <p>Sarcoma UK becomes No 10 Downing Street's Charity of the Year</p> <p>Launch of Support Line services which reached 1,000 contacts in its first year</p> | <p><b>2018</b></p> <p>Clinical trials hub established with over 3,600 page views in the first two months</p> <p>New sarcoma data published to help understand the disease</p> <p>Genomics Research Programme announced with first UK grant of £250,000</p>   | <p><b>2020</b></p> <p>First parliamentary event to raise awareness of sarcoma among MPs</p> <p>First winners of the Tricia Moate award for allied health professionals and nurses</p> <p>First Glitter Ball held in London</p> <p>The Support Line team doubles in the face of Covid-19</p> <p>Commitment to Early Diagnosis announced and first major policy campaign published with backing of MP Jess Philips</p> <p>Biggest Virgin Money London Marathon in terms of amount raised through the first ever virtual race</p> |
| <p><b>2013</b></p> <p>Richard Whitehead becomes first ever Patron of Sarcoma UK and receives an MBE</p> <p>First Sarcoma UK runner in the Virgin Money London Marathon</p>   | <p><b>2015</b></p> <p>NICE publishes Quality Standard for sarcoma</p> <p>First patient/ researcher event 'Talking Research' held in Manchester with Richard Whitehead</p> <p>First National Sarcoma Patients survey launched</p>   | <p><b>2017</b></p> <p>First Chris Martin Memorial Quiz</p>  | <p><b>2019</b></p> <p>Sarcoma UK launches a new brand with a fresh, modern look</p> <p>Downing Street reception to launch the Chris Martin Fellowship</p> <p>Launch of NHS England Sarcoma Service Specifications</p> <p>Support Line extends and regulates its hours and introduces text service</p> <p>Publication of report, <i>The Loneliest Cancer</i>, launches Sarcoma UK's biggest national awareness campaign</p> <p>Sarcoma UK works with the Royal College of Gynaecologists to change recommendations and consent advice on morcellation for women having a hysterectomy or myomectomy</p> |  |

# Tackling sarcoma together: our strategic approach

## Our long-term vision

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

## What this means for people affected by sarcoma



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



Patients will live longer



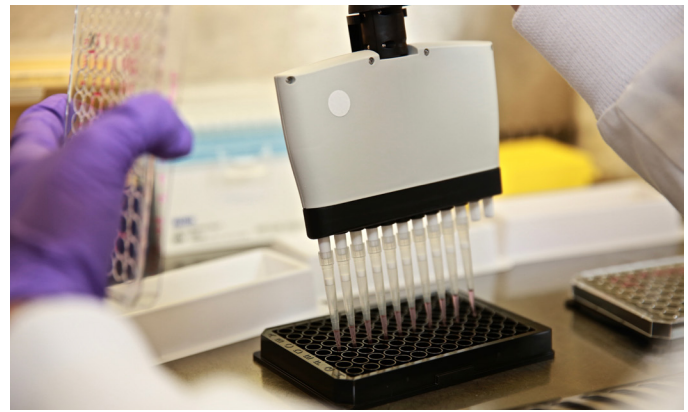
Patients will have better experiences of their sarcoma

## To achieve this over the next three to five years we will focus on:

- Improving education on sarcoma for healthcare professionals.
- Increasing awareness of sarcoma.
- Improving referral and access to scans.
- Prioritising research into the early diagnosis of sarcoma.
- Ensuring patients have more treatment options.
- Ensuring all care is given at specialist centres or involves sarcoma multi-disciplinary teams.
- Supporting more targeted treatments.
- Improving our understanding of sarcoma and how it develops.
- Funding research to improve outcomes and quality of life.
- Ensuring access to the most appropriate care and support.
- Ensuring patients have more access to reliable, transparent information.
- Enabling patients to have access to peer support.

## What we will do

Our strategy is our road map to tackle sarcoma together. The next five years will bring challenges as well as opportunities and we need to be clear about how we will keep on track. Our mission is to ensure everyone affected by sarcoma receives the best treatment, care, information and support available and to create the treatments of the future. By focusing our efforts in four key areas, we can deliver on that pledge together.



# 1

We will equip and empower people affected by sarcoma.

# 2

We will fund world-class research.

# 3

We will build strong and productive relationships with healthcare professionals.

# 4

We will work with the sarcoma community to achieve earlier, accurate diagnosis.

## What we need to make it happen

To do this Sarcoma UK needs to:

- Understand what patients want and involve them in all aspects of our work.
- Improve the data and insight we have on sarcoma.
- Develop strong, diverse income streams.
- Have effective governance and operations.
- Build strong relationships with healthcare professionals.
- Better engage with all people affected by sarcoma and their families, including historically harder to reach groups.
- Invest in and make greater use of digital technologies.



# We will equip and empower people affected by sarcoma – together

**Everyone who needs our help has a different experience and knowledge of sarcoma. We strive to understand what patients want – and need – so it’s clear how we can best make a difference. That’s not just in talking directly with patients but in ensuring that those they trust have the right information and resources.**

In developing this strategy, we found a strong desire for more information around the time of diagnosis, whether from healthcare professionals or from our own support services. That crucial point, which marks the start of a sarcoma journey, was for many people an introduction to something they knew nothing about.

Our patient survey found that an overwhelming majority of people first heard the term sarcoma from a cancer consultant or surgeon. Worryingly, a total of 58 per cent of respondents told us that this first diagnosis was not effectively explained or could have been better.

Whether information and awareness about sarcoma comes from clinicians, leaflets, a website, or our Support Line team, we know that it is vitally important. Patients, their family and friends all need accessible support and information at every step of the sarcoma journey.

Our focus will be to build on the resources, information and support which have been so important since Sarcoma UK was founded. Our Support Line advisors are in touch with hundreds of people every year, with the top three topics mentioned being diagnosis, support and treatment. With targeted resources, and more focus on providing information in the ways that it is wanted, we will continue to support more people with sarcoma. We also know that information and updates about our research are valued so we’ll strengthen our communications about our scientific work and its impact.

No one should feel excluded from our services or resources. That’s why we will work harder in targeting those communities who have been harder to reach, such as people from ethnic minority backgrounds, and ensuring that they have access to the information and support they need.

## How?

- We will aim to reach everyone who is affected by sarcoma with our support and information, particularly those groups such as those from any ethnic minority community who we have failed to reach previously.
- We will engage with people closer to the point of diagnosis.
- We will support patients at every step of their sarcoma journey.



# 1.4%

of all cancer diagnoses in the UK are sarcoma.



# We will support world-class research – together

Research is the key to unlocking the secrets of sarcoma through asking fundamental questions. In time, this clear focus will lead to better care, more accurate diagnoses, more treatments and a better quality of life.

Sarcoma is a cancer that has not seen the investment that other cancers have. However, that has started to change thanks to the generosity of our supporters and the work of other organisations as well as Sarcoma UK.

By 2020, Sarcoma UK had invested more than £3.5 million across 56 research projects large and small. That funding has resulted in more than a decade of research in the laboratory and the clinic, supporting PhD students in the first steps of their sarcoma careers and seeing major new trials get underway.

Our supporters have told us that research is their highest priority and want us to invest in that hope for the future. With a unique role as a link between the patient community and world-class scientists, we are best placed to harness progress in our understanding of sarcoma, and translate that into improving treatments and making a difference to people's lives.

Our funding decisions need to reflect the priorities of patients; in informing this strategy, those affected by sarcoma told us that research into developing treatments and early diagnosis was key. Investing in developing the next generation of sarcoma research leaders and integrating with the research community is essential in ensuring our research brings about real progress.

We will build on the success of our strategic investment in genomics, and continue with focused research calls in priority areas. A balanced and broad research programme with greater flexibility will enable us to support the most promising research projects, no matter what size they are or what subtype of sarcoma they focus on.

Our scientific work is so crucial that we have developed a dedicated research strategy, ***Finding Answers through Research***, which maps our priorities for the next five years and shows how we will deliver in areas that will have the biggest impact.

## How?

- We will fund and support the next generation of sarcoma researchers and encourage networking and collaboration.
- We will combine our funding streams to increase flexibility and efficiency.
- We will involve people affected by sarcoma in our research programme so that it is better informed by their experiences and priorities.
- We will launch targeted calls for funding in priority areas of research.
- We will work more closely with the sarcoma research community to shape our research programme and priorities.

## Finding Answers through Research – Our Research Strategy 2021–2026

Sarcoma UK's research strategy, published alongside the organisational strategy, is the result of a great deal of input from a wide variety of interested parties. It is built on these six key pillars:

- Focusing on patient priorities.
- Integrating with the research community.
- Funding a balanced, broad research programme.
- Building collaboration.
- Developing the next generation of research leaders.
- Communicating research progress.

This framework enables us to take a leading role in shaping the research agenda while allowing us to be agile and flexible enough to react to changes. While we have come a long way over the last ten years, we know that we cannot do this alone. Working in collaboration with the diverse communities that make up our key partners will be critical in achieving our research ambitions and ultimately making a difference for everyone affected by sarcoma.

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## The corporate supporter perspective: The Analyst

**The Analyst, an independent equity research firm in Wandsworth, London, has supported Sarcoma UK since 2011. The partnership is the legacy of Jonny Scriven who was diagnosed with advanced sarcoma while in his early thirties.**



Mark Hiley, Managing Partner and Founder (pictured), had worked with Jonny at Fidelity since they were 21. They were setting up The Analyst together with other former colleagues on board, when Jonny was diagnosed.

“Jonny had always had complaints with his joints, and aches and pains, and saw every specialist under the sun,” Mark recalls.

“He was told that the primary tumour was in his hips, but it had spread much further, including to his back.”

In Jonny’s last few weeks, Mark promised to give Jonny’s percentage stake (five per cent) in The Analyst to Sarcoma UK, the charity that had supported him after his diagnosis.

“It was the obvious choice – the charity meant a lot to Jonny and had given a lot of information as well as help through the Support Line.”

Ten years on, the commitment to the charity has evolved beyond that generous funding of more than £100,000 a year.

“Our relationship has become more than the donation; the businesses have grown together and developed a close relationship,” says Mark. “It’s keeping Jonny’s memory alive.”

There have been joint social events, visits to each other’s offices, and shared support on levels beyond a financial link.

“There’s a nice cultural spirit and the two organisations are of a similar headcount. We’ve given some resources, and tried to offer support and skills where we can.

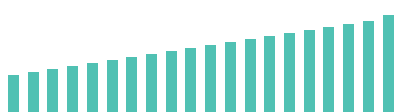
“It’s one of our primary motivations and a real highlight of the year. It’s been heartening to grow the business and our support, and to see how much impact it can have, especially on a small charity. Sarcoma UK definitely punches beyond its weight.

“The link has been an extra motivation for The Analyst team; we always update them and get a lot of positive feedback. It’s nice to have our support aligned with our growth.”

There has also been individual fundraising; last year, Mark’s brother-in-law ran the Virgin Money London Marathon. A team bike ride in Richmond Park and joint branding on the strip of Worcester Park Colts football team shirts have also raised funds and awareness.

As for the future, Mark looks forward to Sarcoma UK’s funded research producing results for patients.

“This would have a massive return on investment and a bigger effect on other cancers; it would be great to see that pay off.”



**Sarcoma survival rates have been very gradually increasing over the last two decades in the UK.**

**78%**

**of people diagnosed with sarcoma in the UK will live for at least a year.**

**40%**

**of people in the UK first heard about Sarcoma UK through word of mouth from a friend or family.**

# We will build strong and productive relationships with healthcare professionals

Sarcoma UK has made great strides in developing a collaborative approach with health professionals. This way of working benefits everyone, from clinicians and GPs to those affected by sarcoma. Collaboration is key to ensuring the strength of Sarcoma UK's professional knowledge and a solid evidence base to influence and achieve our shared goals.

Over recent years we have been able to inform and shape the healthcare agenda, whether through successes in the approval and availability of new sarcoma drugs (such as larotrectinib and imatinib), or tapping into patient experiences to impact on professional guidance. Nurses and allied health professionals are the reason that most patients are positive about their care and treatment. In the strategy development survey, sarcoma Clinical Nurse Specialists and oncologists were identified as the most important healthcare professionals in providing support.

Sarcoma UK will strengthen our links to healthcare professionals and support them in their work to ensure that sarcoma knowledge and best practice is shared and enhanced. This will ultimately help patients to feel better equipped with more information to understand their situation as well as more chances to talk through their particular options.

## How?

- We will collaborate with healthcare professionals to engage with consultations on guidelines, appraisals of new drugs and improving delays to diagnosis.
- We will facilitate networking and collaboration among healthcare professionals to encourage the sharing of best practice and service improvement ideas.

## The professional perspective:

**"I see the Support Line as a partnership, adding another layer of caring, impartial advice and support for patients and relatives at any stage of their journey."**

## The patient perspective:

**"Access to a sarcoma specialist nurse is essential. Our two specialist nurses were exceptional and managed to give us comfort and practical support in the darkest of times."**



# We will work together with the sarcoma community to achieve earlier, accurate diagnosis

The theme of earlier diagnosis was the most common aspect highlighted by those who shared their thoughts and insight for this strategy. Patients see a powerful connection between receiving an earlier, accurate diagnosis with keeping more treatment options open and improving outcomes due to earlier intervention. We already know that this area of research is a patient priority.

For healthcare professionals, a greater awareness of sarcoma is seen as essential in achieving earlier diagnosis. Sarcoma UK will help deliver this change by improving all aspects of education on sarcoma and, hopefully, ensuring better knowledge and expertise among those at the forefront of sarcoma care. A groundbreaking report from Sarcoma UK in 2020 called on the Government and NHS to take strong action to ensure faster and more accurate diagnosis for sarcoma patients around the UK. The publication, *Delays Cost Lives*, represented the charity's first big step towards improving early diagnosis for sarcoma and started to open up dialogue around this issue.

Everyone in the sarcoma community has a role to play in helping to achieve earlier diagnosis - whether through better awareness, influencing or research - to help transform the outlook for patients.

## How?

- We will improve the quantity and quality of education on sarcoma for healthcare professionals.
- We will work to improve referral pathways and improve quick access to scans.
- We will influence UK governments, the NHS and other policymakers to improve how sarcoma is diagnosed.
- We will prioritise research into the earlier diagnosis of sarcoma.



## The patient perspective:

**"I wish our GP listened to my husband so he could have been diagnosed earlier, so that we could have more time together with our girls."**

**"Being a nurse in the emergency setting, I had heard of sarcoma, but never really knew the full details. I was told after investigations that I had a GIST (gastrointestinal stromal tumour)... I am so grateful to #SarcomaUK"**



# 5,240

people were diagnosed with sarcoma cancer in the UK in 2016.

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## The research perspective: Dr Rachel Taylor, University College London Hospitals

Dr Rachel Taylor was first awarded a grant from Sarcoma UK for a ground breaking project dedicated to improving the lives of sarcoma patients in hospital.

The development and validation of a patient outcome questionnaire, the Sarcoma Assessment Measure (SAM), was aimed as a tool to improve communication between patients and their clinicians.

**“My hope for the future is for more funding to become available for research into sarcoma.”**

The funding was part of the Roger Wilson Research Award in its very first year (2016), and the study led to a follow-on project managing the fear of sarcoma returning.

Rachel’s important work was recognised at the Royal College of Nursing Awards 2019 by the Excellence in Cancer Research Award.



**“We need to not only improve survival, but we need to improve the quality of survival so people living beyond a sarcoma diagnosis are able to realise their goals and potential when treatment ends.”**

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## The patient perspective: Isobel Sheppard

**“The Sarcoma UK Support Line has been a real lifeline. Just having someone to talk to who understands what you are going through and who is a sarcoma expert has made a world of difference.”**

Teenager Isobel Sheppard was diagnosed with synovial sarcoma, a type of soft tissue sarcoma, when she was 12. She was sent home from school due to severe pain which her mum initially thought was growing pains. Isobel’s treatment included chemotherapy and surgery, including an amputation of her leg.

“She was doing really well with chemo when we found out that she would need to have her leg amputated,” says Isobel’s mum, Samantha Sheppard. “The tumour was wrapped around her nerves and blood supply so an amputation was the only way to go.

“It came as a real shock, but Isobel was so incredible. We’re slowly but surely getting back to normal now, or as close to normal as we can. Isobel got ready to go back to school this September and she’s not stopped her swimming which she really loves. We’re so proud of her.”



# Our approach

## How you helped develop our new strategy

From the start, we have been keen to ensure that our new organisational strategy is informed by evidence and the involvement of the sarcoma community: patients and their families, other supporters, healthcare professionals, sarcoma researchers, Sarcoma UK staff and trustees.

Those involved have provided insight and thoughts through surveys, research, workshops and one-to-one interviews.

A total of 300 patients and their families provided feedback through in-depth surveys, building on the National Sarcoma Survey 2020. We also carried out tailored surveys of healthcare professionals and researchers to ensure their opinions were considered, with strong engagement.

Additionally, we discussed the specific priorities for our research work with different groups, including research grant holders, funding panel members and other key individuals within the field.

Encouraging discussions with other charities have focused on future plans and approaches, areas of synergy and opportunities for collaboration.

We held workshops with patients and supporters which explored specific aspects of the strategies; research priorities, support and support groups, diversity and inclusivity, mental health and wellbeing, and fundraising.

Every one of these different elements has helped us in shaping the strategy – a process led within Sarcoma UK by a strategy working group involving staff and trustees.

Thank you to everyone who has played a part. Your support, time and insights have been incredibly valuable in shaping this document and ultimately helping us to tackle sarcoma together.



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**The research perspective:  
Dr Paul Huang**



Dr Paul Huang, leader of the Molecular and Systems Oncology team in the Division of Molecular Pathology at The Institute of Cancer Research, London, who specialises in rare cancers.

**“A lot of the research has been driven by academic researchers, particularly with charity partners to push the research and discovery of drugs forward. We are one of the few communities that has to work together. We see the value of collaboration in pooling our resources and patients.”**

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**The patient perspective:  
John Young**



Long-term Sarcoma UK supporter John Young, pictured with wife Sue, was diagnosed with liposarcoma in 2016. Following surgery and radiotherapy, John is now in remission.

**“I am a strong believer in raising awareness of sarcoma. When I was diagnosed, I was the first case my GP had seen in 17 years in practice and I don't think that this is untypical.**

**“Recognising sarcoma helps early diagnosis which improves the chances of successful treatment and outcomes. I feel that anything I can do to help is worthwhile.”**

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

This strategy is our road map to tackling sarcoma together.

With your support, we can continue to build on the progress of our first decade and focus our efforts where they will make the most difference for people affected by sarcoma.

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 sarcomauk  
 sarcoma-uk  
 020 7250 8271

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**Sarcoma UK**  
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