

Finding Answers through Research: Sarcoma UK's Research 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

Our research has come a long way since Sarcoma UK awarded its very first project grants in 2009.

Sarcoma is a cancer that has felt left behind by research for a long time, but now we're starting to see a real momentum for change.

In the past few years there have been some substantial infrastructure grants awarded in sarcoma, a number of major new trials getting underway and new treatments coming to the clinic. We need to build on this progress and continue to see sarcoma scientists at the forefront of cancer research.

In developing this ambitious strategy, our supporters told us that research is their top priority. They want us to invest in hope for the future. As a link between the patient community and the scientific community, Sarcoma UK can be the catalyst for change.

This is a subject very close to my heart. My mum died from sarcoma so I know first-hand the uncertainty it brings and the desperate need for answers.

Now is the time to capitalise on our unique position and our research achievements to deliver on our ambitions. We will continue to push forward and translate progress in our understanding of sarcoma into improving treatments and, ultimately, making a difference to people's lives.



**Dr Sorrel Bickley,
Director of Research,
Policy and Support**

The patient perspective: John Young

“The vital work of Sarcoma UK is entirely dependent on voluntary donations and fundraisers like myself. I have seen first-hand the difference that this makes for everyone affected by sarcoma.”

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

Just a year after surgery he ran the Great North Run with his wife Sue and in 2019 he completed his 12th Great North Run at the age of 74, again with Sue, 70. This was a fantastic achievement for the pair who have 10 grandchildren and have raised more than £2,000.

Sue had been keen to run the race again in 2020 but sadly it did not go ahead due to Covid-19. So she kept busy in lockdown running a roadside plant stall to raise funds for Sarcoma UK.

John lent his support to Sarcoma UK’s first parliamentary drop-in event in 2020, which was attended by his local MP, Rishi Sunak. He is also one of Sarcoma UK’s Patient Voices, helping to raise awareness.



“Even in these uncertain times, it is only through the determination and commitment of the charity and its supporters that Sarcoma UK can continue to fund pioneering research and be there for everyone who needs them.”

The research perspective: Dr Paul Huang

“The small numbers of rare cancers, including sarcoma, pose several challenges – there is a poor investment in research and a lack of interest and awareness. We are playing catch up in many, many respects.”

Dr Huang is 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. He is leading one of the latest PhD projects funded by Sarcoma UK in 2021 to explore and investigate new treatments.

The study over almost four years focuses on analysing tumour types and blood samples in angiosarcoma, a rare type of soft tissue sarcoma. Being able to develop new treatments and manage sarcoma in more targeted ways will ultimately make sarcoma treatments kinder and more effective.



“There is a lot of optimism out there, and a lot of momentum, with the ability to get information about patients through genomic science, and the potential of artificial intelligence. Hopefully this will drive us to a future where there are no longer complex diseases, where we can get a better understanding of the biology, but also devise smarter trials to deliver drugs to our patients.”

Our strategic approach

It was very important to us that our new Research Strategy is the result of evidence and insight from those who are most involved and affected by our work.

Over the past few months, we conducted a series of exercises to inform the development of this document and ensure that a variety of views, experiences and insight from the sarcoma community were taken into account.

The many different elements of this feedback involved:

- A survey of people affected by sarcoma to determine their priorities.
- Focus groups with people affected by sarcoma.
- Feedback from members of the research community, including our Research Advisory Committee and current grant holders.
- Discussions with other charities working in sarcoma and in the broader medical research field.
- Analysis of the outputs and impact of our grants funded to date.
- An evaluation of our research governance.

We were heartened by the positive reaction to our research investment over the last decade. Overall, our funding processes were regarded as fair and transparent, and we were seen to have a good balance of research.

Our research is a key building block in the ambitions of our Sarcoma UK's new organisational strategy, **Tackling Sarcoma Together**, published alongside this document.

As we look ahead to the next five years, our research programme will evolve in order for us to make the most progress for people affected by sarcoma. Thank you to everyone who has given their time and insights to help shape this strategy and the future of our vital research.



The picture for sarcoma research is starting to change.

Research is at the heart of everything we do. It has never been more important for us to keep pace with scientific advances and bring new hope to the sarcoma community.

This research strategy has been developed in parallel with a new organisational strategy as Sarcoma UK enters its tenth anniversary year.

This is a timely opportunity to build on our research progress to date and ensure that we concentrate on where we can make the biggest difference. Delivering on our research priorities lies at the heart of achieving our long term scientific and charity goals for all of those affected by sarcoma.



Richard Davidson,
Chief Executive

Our Research Strategy – the core principles



Focusing on patient priorities

Your views help to shape our research to better reflect patient priorities and perspectives



Building collaborations

We work in partnership and develop networks within the community



Integrating with the research community

We work closely with our grant holders and the wider research community



Developing the next generation of research leaders

We support a PhD studentship programme and invest in the future of sarcoma research



Funding a balanced, broad research programme

We support a wide-ranging portfolio of projects



Communicating research progress

We share information and raise awareness about sarcoma research and its impact

15

people are diagnosed with sarcoma every day in the UK. That's about 5,300 people a year.

1.4%

Sarcoma diagnoses now make up about 1.4 per cent of all cancer diagnoses in the UK.

1 in 3

people wait more than six months to receive an accurate diagnosis after they first consult a healthcare professional.

Our Research Strategy – what we will do

Focusing on patient priorities

Your views help to shape our research to better reflect patient priorities and perspectives

The insight from patients into our research funding has been immensely useful in helping us to be clear about our focus in research. Funding for research into developing new and better treatments was rated as the highest priority for patients, and almost 70 per cent of survey respondents wanted to know more about research because they were interested to know about what hope it brings for them or their loved ones.

From 2009 to 2019 Sarcoma UK funded 56 research grants, investing a total of £3.5 million. While we have invested in grants of all sizes, early diagnosis has not necessarily been top of the agenda, and we have received very few grant applications focused on this area. In our 2020 survey we heard very clearly from patients that they see it as a high priority, however (see graph below). We will respond by shaping our future funding to better reflect this preference.

Building on invaluable stakeholder feedback in developing this strategy, we are keen to continue involving patients and their loved ones more closely with our research plans. We believe that this approach will facilitate a stronger focus on what matters to people affected by sarcoma and cement a framework of research which offers the most long-term benefit and impact for patients and their needs.

How?

- We will reflect the top priority for patients in our scientific investment – new and better treatments.
- We will increase focus on the second priority area, research into early diagnosis, in our research programme.
- We will shape our wider research investment to better reflect patient views.
- We will introduce a patient involvement programme, bringing patients and those close to them onto our research panels and introducing lay reviews for applications. This will enable patients to inform our funding calls around the areas that are most important to them.

“While other types of cancer have become much more survivable over the past 30 years, sarcoma has missed out for decades due to its rarity. The consequence is there is still no effective chemotherapy for my type of cancer, and five-year survival is less than 50%. That is a terrifying position to be in.”

Kate Hardy



Integrating with the research community

We work closely with our grant holders and the wider research community

Over the last decade and more, Sarcoma UK has invested time, effort and vital funds into developing a solid research programme and working closely with those who are pillars of the sarcoma research community.

That integration has paid off in the impact of our funding and the longevity of many of those relationships, whether a small pilot grant or a laboratory research project. This is underpinned by the excellence of our governance; our Research Advisory Committee of scientific and clinical experts across a broad range of disciplines which oversees our grant rounds.

We plan to establish a strategy panel to focus on shaping and guiding our research programme at Sarcoma UK. Its function will be forward looking in setting priorities and building collaborations, but also evaluating work to date in terms of the impacts of our funded grants.

One of the more recent developments at Sarcoma UK has been a major strategic investment into genomics – key to unlocking the secrets of sarcoma and developing new treatments. We have been hugely excited about the potential of genomics in sarcoma and launched our transformational Genomics Research Programme in 2018 with the aim of bringing about a step change in research.

We believe that continuing to run focused research calls in key areas, as we did with genomics, is the way forward for our programme.



£500,000

To date we have invested £500,000 into genomics research through this programme, most recently funding a two year £250,00 project at the University of Birmingham led by Professor Andrew Beggs. This work will help pinpoint why sarcomas don't respond well to cancer immunotherapies and could lay the foundations for the development of new, more targeted treatments.

“The financial support of Sarcoma UK has been transformative. We would not have been able to do this work without it. No other cancer type has access to such cutting-edge technology.”

**Professor Andrew Beggs,
Principal Investigator, University of Birmingham**

The needs of sarcoma scientists in terms of financial support have never been greater. We will hope that our funding will serve as a catalyst to unlock further sources of financial support, enabling researchers to expand their research and ultimately translate their findings into patient benefit.

How?

- We will build on the success of our strategic investment in genomics, and continue to support focused strategic research calls in priority areas.
- We will set up a strategy panel to guide our research programme. This will support strategic investment, shaping priorities year by year, as well as reviewing the impact of our grants and steering collaborations.
- We will work closely with grant holders to help attract additional funding and translate research findings into impact for patients.

Funding a balanced, broad research programme

We support a wide-ranging portfolio of projects

Our approach over the last decade has been to support the best and the brightest minds in the scientific community, whether funding laboratory-based projects or clinical research. We've also invested in projects focused on one specific sarcoma subtype, as well as those looking into topics that are relevant to all sarcoma subtypes. Such flexibility in the breadth of research funded by Sarcoma UK has worked well both in scientific terms and for our stakeholders; the vast majority of survey respondents believed that the balance of funding was about right, or should focus more on broader projects so that more sarcoma subtypes could benefit.

We will continue to adopt a balanced and broad approach which enables us to consider research options for their potential impact rather than their grant type. We will increase the flexibility of our programme, expanding the range of grant types and welcoming applications from both clinical and laboratory researchers. This will also help to ensure that our programme is adaptable in uncertain times.

A closer look at the impact of small grants has revealed that they represent a worthwhile investment when it comes to their impact and their potential as a crucial building block to attract further funding. This reinforces our ethos for a flexible, balanced portfolio with the long-term aim of improving the lives of people with sarcoma.

How?

- We will be flexible in funding small and large grants into cause, diagnosis, treatment and quality of life.
- We will combine our laboratory and clinical rounds to increase flexibility and efficiency. This will open up small grant funding for laboratory projects and allow researchers to shape their application to the most appropriate grant size.
- We will maintain a balance of funding between subtype specific projects and projects looking across multiple sarcoma subtypes.
- We will ensure a balance of research investment into laboratory and clinically based projects.



Building collaborations

We work in partnership and develop networks within the community

A collaborative approach runs through every aspect of Sarcoma UK's work, and never more so than in the research programme. This underpins the funding journey, working hand in hand with basic scientists, imaging specialists, pathologists, oncologists and surgeons who share a passion to improve outcomes for people with sarcoma. We want to expand our partnership work, both through structured collaborations and adopting an informal approach to teamwork.

Workshops have been a relatively recent example of flexibility and partnership in action. The scheme and its support can be used to facilitate researchers to come together, providing space to meet, discuss ideas, and plan applications. Since the scheme launched in 2019 we have had the opportunity to support only a small number of workshops. However, the response has been overwhelmingly positive and therefore we aim to continue to focus on this scheme.

Our research grant funding also serves as a tool to drive collaboration and dissemination of findings to the wider research community. There have been over 100 presentations and workshop sessions given by our grant holders to date.

The power of partnership is not necessarily confined to the research field, but involves everyone who has an interest in sarcoma. As part of developing this research strategy, we held encouraging discussions with other charities and funding bodies which have already led to thinking around areas of synergy and opportunities for collaboration. The power of shared aims is one to be harnessed even further in delivering our ambitions.

How?

- We will foster collaborations in sarcoma research through informal matchmaking and workshop funding.
- We will work in collaboration with other groups and organisations who have an interest in sarcoma or a focus on specific subtypes.
- We will continue to fund workshops to build networks within the community and encourage new collaborations.

Developing the next generation of research leaders

We support a PhD studentship programme and invest in the future of sarcoma research

At Sarcoma UK we appreciate the value of PhD projects as supporting scientists who are starting out on their careers is the bedrock of scientific research.

Since the launch of our studentship programme in 2016 we have proudly supported eleven PhD projects in laboratories across the UK. Despite the uncertainties of 2020, thanks to the generosity of our supporters, we were very pleased to announce our funding for three new PhD projects with an investment of £360,000. The successful applications from a very strong field are looking at potential new treatments and treatment models for a variety of different sarcomas.

Our commitment to supporting PhD students goes beyond funding, not only through working directly with scientists, but in connecting them as a valuable student network. This long-term approach will reap benefits for everyone, including those at the forefront of the research breakthroughs of the future, as well as those affected by sarcoma.

How?

- We will continue to support PhD studentships as a priority, and strengthen our support for students through establishing a network and working with them directly.

Communicating research progress

We share information and raise awareness about sarcoma research and its potential impact

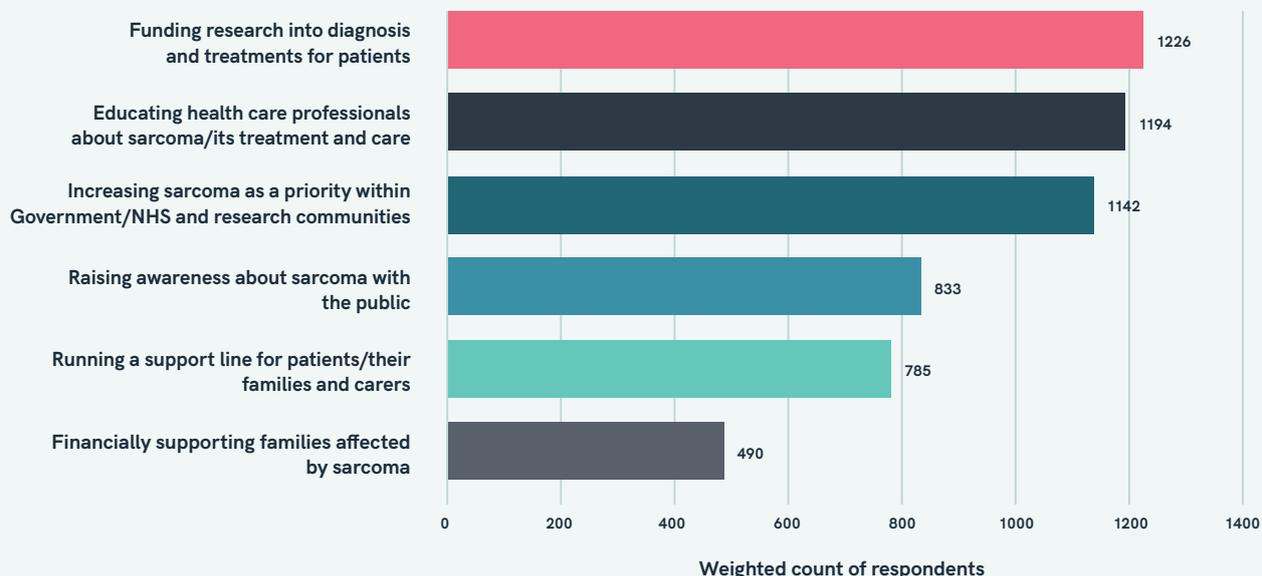
Our new organisational strategy paints a picture of the importance of information, awareness and education across the broad spectrum of our work. Supporters want to know more about sarcoma, but also about how our research programme is making a difference. For instance, with early diagnosis identified as one of the highest patient priorities (see below), we want to be able to share engaging content about our progress in this field, and other areas that people affected by sarcoma care about. Research is exciting and future-focused, with many milestones along the way. Sarcoma UK has a responsibility to update our supporters about the advances and potential patient benefit achieved through the work they have supported.

Our links with research projects and grant holders do not stop once a grant has ended. We follow up on the impact of our funded work and promote its significance for the benefit of all of those in the sarcoma community.

How?

- We will share information about our funded projects and their impact while they are ongoing and beyond.
- We will be proactive in monitoring the impact of our grants beyond completion lifetimes.

What priorities should Sarcoma UK have in improving the experience of sarcoma?



The patient perspective: Maddie Cowey

Maddie Cowey is a dedicated supporter of Sarcoma UK, fundraising and raising awareness through her blog maddiescancer tales.com.

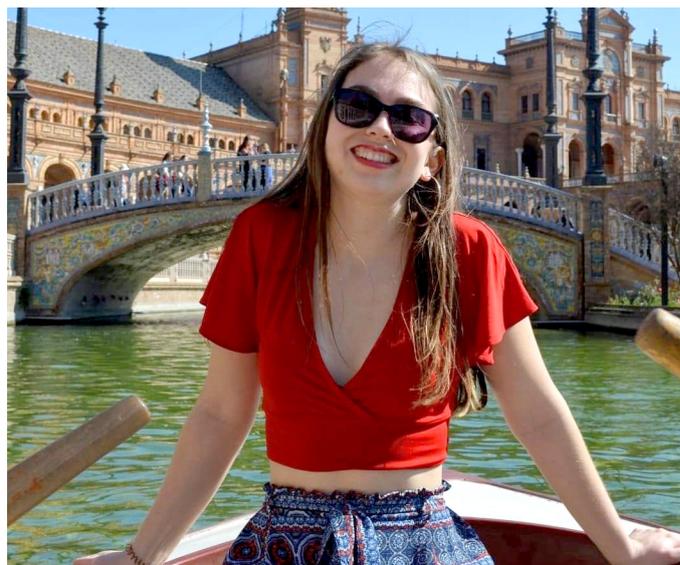
Aged 18, she was diagnosed with Alveolar Soft Part Sarcoma (ASPS), a rare soft tissue sarcoma, after finding a small lump on her shoulder.

Five years later, Maddie is passionate about the importance of research and the need for early diagnosis after her own experience of waiting five months to receive a sarcoma diagnosis.

“GPs will see hundreds of tumours in their career but might just see one sarcoma patient. It is no wonder that we are so often brushed under the carpet. Sarcomas are difficult to recognise and medical professionals need to be better equipped to do so.”

In September 2020 she began chemotherapy for tumours in her lungs which, three months later, had not only stopped growing, but had shrunk.

“Research into sarcoma is severely lacking due to its rarity and patients are therefore diagnosed extremely late, have a poor prognosis and few treatment options. I vow to make a change to this stark reality.”



“I wish there was an easier way to help Sarcoma UK, and that research could just be funded by magic. Until that becomes possible, I will keep on finding ways to fundraise.”

The PhD student perspective: Panos Balaskas

A grant from Sarcoma UK to explore a sarcoma that unusually affects older people has helped to improve developments in treatments and diagnosis of the future. The two year study at the University of Liverpool’s Institute of Ageing and Chronic Disease was led by Professor Mandy Peffers, Principal Investigator.

The idea originated from co-investigator and PhD student Panos Balaskas who became interested in sarcoma after his main PhD work into osteoarthritis.

The team focused on a better understanding of chondrosarcoma – a cancer of the cartilage – through detailed investigation of the molecular mechanisms in the thighbone and knee.

“Most sarcomas affect younger people, but this type of sarcoma affects mainly those over 40,” explained Panos. “Sarcoma was a new area for us, and as we got more results, we got more excited.”



“Often there are good ideas, but not necessarily the funding. We are very grateful for Sarcoma UK to have given us a grant and to have been open-minded about our lack of cancer experience.”



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

We fund research to understand more about sarcoma. This will lead to improved care through more accurate diagnoses, more treatments and a better quality of life.

This publication explains how our new research strategy will help us build on our progress to date by investing in world-class science and research and, ultimately, making a difference to people's lives.

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