Strategy
2014 - 2020
Transforming the landscape for sarcoma
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Introduction

*Transforming the landscape for sarcoma* sets out the goals and priorities which we think must be tackled to improve the situation for people diagnosed with sarcoma and their families. As a small and young charity, we don't presume to be able to deliver these singlehandedly. However, as the main organisation for all types of sarcoma in the UK, we aim to inspire the whole sarcoma community – people affected by sarcoma, supporters, healthcare professionals, the NHS, researchers, and other charities – to share our vision for the future and help it become reality for the 12,000 people living with sarcoma and their families. Our strategy sets out the framework that Sarcoma UK will use to direct our work during the next 6 years in our efforts to transform the landscape for sarcoma.

Sarcoma UK was created by people with first-hand experience of sarcoma – patients and carers – who had identified a clear need for greater information and support. This committed community worked tirelessly to bring together the expertise of the sarcoma world for the first time, recognising that sarcoma needed to be tackled on multiple fronts with a balanced approach. Our first strategy for the future is rooted in, and builds, on this important heritage. It draws on supporters’ opinions and experiences collected through a survey *Shaping our Vision for the Future* carried out in 2012.

Sarcoma UK relaunched as a new charitable company in June 2011 (a merger of two former sarcoma organisations). In these three years, we have made rapid progress in establishing new programmes for research, information and support, as well as significantly increasing the profile of sarcoma with healthcare professionals and the public. A secure infrastructure and small but professional staff team ensures this progress will continue.

The development of this strategy comes early in the life of Sarcoma UK. However, the board of trustees recognise that a clear vision for the future will enable us to make maximum impact for the sarcoma community, focusing our efforts where they are needed most.

Lindsey Bennister  Chief Executive
Pippa Hatch, Sarcoma UK supporter and Olympic torch bearer – June 2012
Our mission

To increase knowledge and awareness of sarcoma through groundbreaking programmes that inspire involvement and transform the landscape for everyone affected by sarcoma.
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 some. We seek to inspire everyone in the sarcoma community to achieve our mission.

**Expert**
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.

**Dynamic**
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.
Richard Whitehead MBE, Sarcoma UK’s Patron
(Running from John O'Goats to Land’s End – August 2013)
The current sarcoma landscape

- 10 people every day are diagnosed with sarcoma in the UK
- Sarcomas make up 1% of all cancer diagnoses in the UK
- Sarcomas make up 14% of all childhood cancers (0-14 years)
- Sarcomas make up 11% of all cancer diagnoses in teenagers and young people (15-24 years)
- In general, patients with sarcoma tend to be younger than the majority of cancer patients:
  - 16% of bone or soft tissue sarcomas are diagnosed in patients less than thirty years of age, compared to around 2% of all cancers *
  - 37% of bone or soft tissue sarcoma patients are aged less than 50 years *
- The five-year relative survival rate for all sarcomas is approximately 55% *
- There has been no significant improvement in survival rates for bone sarcomas in the last two decades *
- There has been some improvement in survival rates for soft tissue sarcomas (from 48% to 56%) in the last two decades, however overall survival is still poor compared to other countries eg Scandinavia and Italy, and other cancer types. *

Improvements in data collection by the National Cancer Intelligence Network, and the introduction of the National Cancer Patient Experience Survey in 2010, have provided a clearer picture of the current landscape for sarcoma. Delayed diagnosis, late presentation, difficulties accessing sarcoma specialist services and one of the poorest patient experience of any cancer – these are the major challenges facing us in our task to transform the landscape for sarcoma.

* England data
Our goals

Our goals address the key challenges of the current sarcoma landscape.
Goal 1

More people will survive sarcoma

We are determined to improve earlier diagnosis and increase awareness of the signs of sarcoma so that more people survive sarcoma.

Delayed diagnosis is a major issue for sarcoma and is likely to have a direct impact on survival rates. Data shows that outcomes for people diagnosed with sarcoma become steadily worse with increasing size of the sarcoma. The smaller the sarcoma at diagnosis, the better the chances of survival. However, published data and patient-reported evidence currently paints a picture of repeated visits to general practitioners before referral for investigation; delays by patients in seeking medical advice until symptoms are advanced; and lack of knowledge and education in primary care of the signs, symptoms and seriousness of sarcoma.
Targets

- The five-year relative survival rate for all sarcomas will have increased to at least 60% by 2020.
- 80% of people with suspected sarcoma will be referred to hospital for further investigations on their first or second visit to their GP (compared to 2013 where one third of sarcoma patients visit their GP three times or more before referral).
- 60% of people will be aware of the term 'sarcoma' and the majority of these will know that sarcoma is a form of cancer.
Goal 2

More will be known about the causes of sarcoma

We will support and lobby for increased investment in high quality innovative research, in order to find answers, breakthroughs and ultimately a cure.

Basic and translational research into sarcoma in the UK is focused around a small number of active teams and individual clinicians, many of whom also play a role in research internationally. The numbers of patients recruited into sarcoma clinical trials in the UK is currently the highest ever. However, the National Cancer Patient Experience Survey (2013) shows that only a third of sarcoma patients are told about opportunities to take part in research.

The annual spend on sarcoma research in the UK is £2 million (2012), compared to £400 million invested into cancer generally each year. A complex disease such as sarcoma requires significantly higher levels of investment in order to bring about breakthroughs in understanding the causes, developing new treatments and ultimately preventing sarcoma.
Targets

- 70% of sarcoma patients will have been told about opportunities to take part in research (compared to 34% in 2013).
- The total national investment in sarcoma research will have increased by at least £1 million to reach £3 million by 2020.
Goal 3

Everyone affected by sarcoma will have access to the best treatment and care

We will work collaboratively with sarcoma specialist health services to provide high quality information and support to improve the experiences of sarcoma patients and carers within the health service. We will be the authoritative voice of people affected by sarcoma, influencing standards of treatment and care.

There has been significant progress in managing sarcoma in the NHS through the publication of NICE Improving Outcomes Guidance for sarcoma in 2006. This provides the framework for specialist commissioning of NHS sarcoma services within regional specialist centres and multi-disciplinary teams (MDT). Evidence shows that patient outcomes are improved when treatment is within specialist centres.

However, data and patient-reported evidence currently indicates that over 40% of sarcoma patients are still not treated in sarcoma specialist centres or under the care of a sarcoma MDT. Surgical treatment of sarcoma is often undertaken by non-sarcoma surgeons in local hospitals, with poorer outcomes for sarcoma patients. Lack of clarity and understanding within the NHS of the pathways for sarcoma patients from diagnosis through to end of life care is a key factor.

The experiences of sarcoma patients within the NHS are some of the worst compared to other cancer types. The National Cancer Patient Experience Survey 2013 highlights particular problems around the provision of written information to patients throughout their diagnosis and treatment despite the availability of high quality independent sarcoma patient information from charities such as Sarcoma UK. Not enough patients and relatives are told about where they can get additional support from local support groups or national patient organisations.
**Targets**

- The NHS experience of sarcoma patients will have moved from being one of the worst of all cancers, to being amongst the best of the rarer cancers.
- 100% of people diagnosed with sarcoma will be treated under the care of a sarcoma multi-disciplinary team (compared to only 60% in 2013).
Team Woodcock, Peking – Paris vintage car rally in memory of Louis Woodcock – May 2013
Strategic priorities

This is the work we will do to achieve our goals.
Priority 1

Initiate change to raise awareness and improve care

- To increase the visibility of sarcoma and how it impacts on individuals and families, so that the public are familiar with sarcoma and its signs and symptoms.

- To influence sarcoma health services so that sarcoma patients receive timely and high quality treatment and care, from diagnosis through to end of life care.
We will have...

- Brought together sarcoma data and patient experiences into a strong evidence base to understand and interpret the current landscape and monitor change.
- Launched targeted campaigns and communications to illustrate the impact of sarcoma and to lobby for change.
- Mobilised the sarcoma community to help us push for greater public awareness and improvements in sarcoma health services.
- Built up a strong network of Sarcoma Voices - patient advocates working within local sarcoma services and national bodies – ensuring the patient perspective is heard.
- Successfully lobbied for sarcoma to be recognised as a policy priority within NHS cancer services, ensuring that national pathways for diagnosis, treatment and follow up care are in place.
- Worked collaboratively with the British Sarcoma Group, National Sarcoma Forum, Scottish Sarcoma Network and other national and regional initiatives, to deliver education programmes and promote best practice in sarcoma care across the UK.
- Launched a new education initiative to promote greater recognition of the signs of sarcoma and improved understanding of the pathways for referral to specialist centres.
- Championed the vital role of the sarcoma Clinical Nurse Specialist (CNS) in improving the patient experience of sarcoma so that all sarcoma patients have access to this support.
- Raised the profile of Sarcoma UK publicly and within the health services so that 100% of people diagnosed with sarcoma are aware of our services.
Priority 2

Seek answers through research

- To maximise the impact of our own research programme, and to play a significant role in influencing the national sarcoma research agenda.
We will have...

- Invested over £1million into research by 2020, adding value to the national programme of sarcoma research.
- Monitored and communicated the results of our research investment widely to stakeholders, improving the understanding of sarcoma.
- Lobbied for the total amount invested nationally in sarcoma research to be significantly increased and for new treatments to be quickly and consistently available for sarcoma patients.
- Brought together researchers, clinicians, industry, government, charities and other stakeholders to identify the priorities for research.
- Encouraged and supported patients to play an active role in research.
Priority 3

Support the sarcoma community and provide information

- To extend the reach of our information and support services to all people affected by sarcoma.
We will have...

- Worked across the nations of the UK to ensure all sarcoma patients have access to our services wherever they live.
- Become the first port of call for information and support on all types of sarcoma and insights into the patient experience.
- Developed a complete set of accredited information resources, covering all elements of sarcoma, driven by the needs of patients and carers.
- Developed our website to be the nationally recognised portal for high quality information and support about sarcoma for patients, carers and healthcare professionals.
- Helped to establish sarcoma support groups in association with each sarcoma specialist centre in England; and new support services in Scotland, Wales and Northern Ireland.
- Established new ways of supporting patients, carers and families including information days; peer-to-peer support; and online services.
- Doubled the number of people affected by sarcoma using our information and support services.
Priority 4

Build a strong charity

- To generate the resources needed to enable us to meet the challenges of sarcoma, and to establish Sarcoma UK as the main organisation for all types of sarcoma.
We will have...

- Established a fundraising strategy for income growth, which will have diversified our income streams, providing increased security.
- Increased our annual income from £500,000 to £1.5million.
- Spent no more than 25p of every £1 raised in fundraising costs, in line with the Institute of Fundraising’s recommendations.
- Spent at least 70% of our annual income on charitable activity.
- Doubled our supporter base of stakeholders including patients, carers, families, healthcare professionals, policy makers, researchers, scientists, and the general public.
Reviewing progress

The strategic priorities will inform our operational plans for each year, and progress against these priorities will be reviewed annually and reported in our Annual Review.