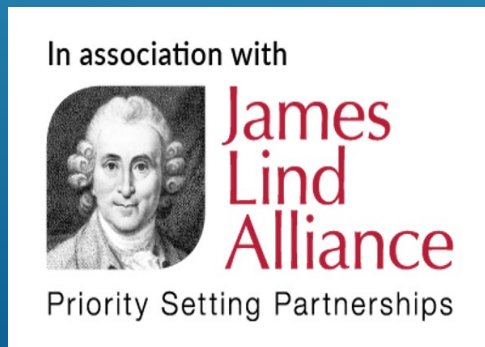


SPINAL SARCOMA PRIORITY SETTING PARTNERSHIP (SSPSP)

David Baxter

Supported by the James Lind Alliance (JLA)



Royal National Orthopaedic Hospital 
NHS Trust

THE IMPORTANCE OF THE PSP

There are over 60 new diagnoses of spinal sarcomas each year in United Kingdom, with many more patients living with the disease at various treatment stages. Spinal sarcoma may present late in the disease course when patients develop neurological deficits, impacting the disease's stage, the complexity of therapeutic procedures, overall survival, and health-related quality of life.

Patients need a combination of surgical treatment, chemotherapy and radiotherapy; these treatments may themselves lead to disability, and patients require long-term follow-up to ensure that the disease does not reoccur. Although the absolute number of patients is small, because of improvements in treatment an increasing number of patients are living longer with complex medical problems.

PRINCIPAL AIM OF THE SSPSP


The aim of the **spinal sarcoma** PSP is to identify the unanswered questions about **spinal sarcomas** from patient, carer and clinical perspectives and then prioritise those that patients, carers and clinicians agree are the most important for research to address.



SCOPE OF THE SPINAL SARCOMA PSP

- ▶ The scope of the **spinal sarcoma** PSP is defined as:
- ▶ patients living with spinal sarcoma identified through the five main clinical centres treating this condition in the UK including Birmingham, London, Manchester/Oswestry, Newcastle and Oxford
- ▶ carers of either patients who are currently living with sarcoma and its long-term effects or those who may have lost a relative or friend to a spinal sarcoma diagnosis
- ▶ clinicians including oncologists, surgeons, radiologists, Allied Health Professionals (AHPs eg physiotherapists, occupational therapists etc), psychologists, play therapists, pathologists who can be identified via the aforementioned treatment centres.
- ▶ charities and patient-led support groups involved either in sarcoma cancer research or who provide support to patients and their families and friends

MAIN STEPS

- ▶ 12 monthly steering group meetings involving a small group of patients, carers, clinicians and charities all with experience of spinal sarcoma.
 - ▶ Design and dissemination of surveys and questionnaires to a wider audience to gain an insight into what uncertainties exist within spinal sarcomas. Areas which may be considered could include symptom recognition and diagnosis, surgical pathways, post operative care, post discharge care and support.
 - ▶ Analysis of responses and further dissemination of revised questionnaires.
 - ▶ Pulling together a list of the top 10 priorities/uncertainties.
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PSP WEBSITE

The screenshot shows the top section of the PSP website. On the left, there are logos for 'PSP', 'Royal National Orthopaedic Hospital NHS Trust', and 'James Lind Alliance Priority Setting Partnerships'. The main header text reads 'Spinal Sarcoma PSP' and 'Making Your Health Our Number 1 Priority'. A 'Get In Touch' button is located on the right. Below the header is a navigation menu with links: Home, Why the PSP is important, Survey, The Team, Groups, Members, Patient Stories, Contact, and More. On the far right of the navigation bar are icons for location, notifications, user profile, and a dropdown menu.



PSP SURVEY

Survey

PSP Survey

This is a national survey collating the views of the entire UK spinal sarcoma community.

We are seeking the input of all those working in or affected by spinal sarcoma, including families, friends, carers and those bereaved by it. This is a unique opportunity for you to have your say in driving and shaping the future of research.

By participating in the survey, you are agreeing to have your priorities included in the UK Spinal Sarcoma Priority Setting Partnership. All submissions will be anonymous and any personal information will be kept confidential. Your research priorities will be analysed and published, but not linked to you or your organisation.

For more information, download our Frequently Asked Questions [here](#) or contact Catherine, PSP coordinator at rnoh.spinal_sarcoma_psp_coordinator@nhs.net to request instructions on how to access the survey in another language or format.

[To the Survey](#)



Sarcoma UK
The bone & soft tissue
cancer charity



**The Royal
Orthopaedic Hospital**
NHS Foundation Trust



Oxford University Hospitals
NHS Foundation Trust



The London Sarcoma Service

GMOSS

Greater Manchester & Oswestry Sarcoma Service



**The Robert Jones and Agnes Hunt
Orthopaedic Hospital**
NHS Foundation Trust



The Newcastle upon Tyne Hospitals
NHS Foundation Trust

THE beatson
WEST OF SCOTLAND CANCER CENTRE



**Belfast Health and
Social Care Trust**
caring supporting improving together



University College London Hospitals
NHS Foundation Trust



**CANCER
RESEARCH
UK**

TEAM

Hanny Anwar & David Baxter – SSPSP Leads

Maryrose Tarpey – James Lind Alliance Advisor

Catherine Siddiqui– SSPSP Coordinator

[SpineSarcoma_PSP \(@spinesarcoma\) / Twitter](#)

PSP JLA link:<https://www.youtube.com/watch?v=BGuTYf5iJQQ>

Further information please contact:

Rnoh.spinal_sarcoma_PSP_coordinator@nhs.net

