

Dear Member

We are establishing a James Lind Alliance Priority Setting Partnership (PSP) in Spinal Sarcoma and would be delighted to share this with you.

Sarcomas are a rare group of cancers that can arise in any part of the body, including bone, tendons, blood vessels and fatty tissues, making them prone to late diagnosis. In other malignancies, early diagnosis has an impact on the complexity of therapeutic procedures, quality of life and survival rates. Over 5000 patients are diagnosed with sarcoma in England each year. Over 600 of these diagnoses arise in bone and approximately one tenth of these, equating to around 60 patients annually, occur in the spine.

Unlike bony sarcomas that arise in the extremities, spinal sarcomas have a relatively poor prognosis, the reasons for which are unclear. Spinal sarcomas, which tend to be smaller in size than those found in the extremities, may present late in the disease course when patients develop neurological deficits. These neurological symptoms often mimic other benign spinal, neurological or musculoskeletal conditions and this in turn, may contribute to a late diagnosis. Treatment tends to involve a combination of surgery, chemotherapy and radiotherapy. As with many malignancies, early diagnosis is essential and surgery is potentially less complex with fewer complications and risks, adjuvant therapies such as chemotherapy and radiotherapy may be more effective and ultimately the prognosis may be improved.

Our primary aim is to bring together patients, carers, clinicians and charities from each step in the patient care pathway, using the JLA process (<https://www.youtube.com/watch?v=BGuTYf5iJQQ>) to determine the top 10 research priorities in Spinal Sarcoma. These will be publicised to help inform future research strategies. A secondary benefit of this process will be to help build and develop clinical, scientific, and patient networks across the United Kingdom to enhance teamwork and cohesion when treating spinal sarcoma.

Research on the effects of treatments often overlooks the shared interests of patients, carers and clinicians. As a result, questions that they all consider important are not addressed and many areas of potentially important research are therefore neglected. The James Lind Alliance (JLA) exists to help address this imbalance. Even when researchers address questions of importance to patients and clinicians, they often fail to provide answers that are useful in practice. Another purpose of the JLA therefore, is to address the mismatch between what researchers want to research, and the practical information that is needed day-to-day by patients and health professionals.

Priority setting partnerships (PSPs) enable clinicians, patients and carers to work together to identify and prioritise evidence uncertainties in particular areas of healthcare that could be answered by research. The JLA method is designed to change the way research funding is granted, and to raise awareness of research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them.

We are planning to hold an introductory, remote meeting via Teams on the 29th September 2021 from 10:00 - 11:00am and would be delighted to welcome you. The agenda for this meeting will be sent out nearer the time but will include:

- A presentation about Spinal Sarcomas by David Baxter (Consultant Neurosurgeon) and Hanny Anwar (Consultant Spinal Orthopaedic Surgeon).
- An outline of the aims of the PSP and how the process will evolve by Maryrose Tarpey (Adviser – James Lind Alliance)
- Question and answer session.

If you wish to attend please reply to Sandrine Slavik via email to rnoh.spinal_sarcoma_psp_coordinator@nhs.net by 15th September 2021. If you are aware of any other individuals who may be interested, then we would be extremely grateful if you would circulate this information further.

We look forward to hearing from you

Kind regards

Sandrine

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