

Top 10 Priorities for Clinical Research in Primary Brain and Spinal Cord Tumours. Final Report of the James Lind Alliance Priority Setting Partnership in Neuro-Oncology

JLA PSP final report (2015)

<https://www.jla.nihr.ac.uk/priority-setting-partnerships/neuro-oncology/downloads/Neuro-Oncology-Group-Final-Report-June-2015.pdf>

For which topic were research priorities identified?

neurooncology

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Brain and spinal cord tumours are rare conditions that can be devastating for those affected and their families. The UK government has expressed commitment to improving the lives of those with rare diseases by 2020. The UK Strategy for Rare Diseases recommends commissioning of high quality research and recognises the value of involving patients at every stage of the research journey.

What was the objective?

to identify the clinical research questions of greatest importance to people living with brain and spinal cord tumors, those who care for them and those involved in their diagnosis and treatment

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

18 months

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: scope agreed on. Step 2: gathering questions: survey inviting questions from members of the public who had experience or interest in brain and spinal cord tumors and professionals dealing with this group of patients, additionally small number of questions from a brain tumor charity patient forum and from UK DUET added, 600 initial individual questions collected. Step 3: data processing: merging duplicate questions, out-of-scope questions removed, check against evidence. Step 4: interim ranking: survey asking participants to select their top 10. Step 5: final prioritization: workshop: Delphi technique with nominal group technique used to reach consensus

Which stakeholders took part?

Patients, carers, clinicians. Survey: over 200 people: patients, carers (=family members or friends) and health professionals. Interim ranking: 227 participants. Workshop: 29 participants: patients, relatives, charity representatives, doctors from a breadth of specialities, nurses and allied health professionals: 14 primarily involved to represent patient perspective and 15 to represent professional perspective.

How were stakeholders recruited?

The survey was publicised widely through the press and relevant charity, health and research organizations.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group.