



# AO Spine RECODE-DCM: Why Prioritize Research in Degenerative Cervical Myelopathy?

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Degenerative Cervical Myelopathy (DCM) is a disabling condition estimated to affect up to 2% of adults.<sup>1,2</sup> It arises when arthritic and/or congenital changes in the cervical spine compress and injure the spinal cord, causing a range of symptoms, including pain, motor, sensory and autonomic deficits to upper and lower extremities, neck and torso. Treatment today is largely limited to surgical decompression.<sup>3</sup> While this will offer most meaningful benefit, few make a full recovery, contributing to among the worst quality of life scores of chronic disease,<sup>4</sup> and high levels of dependence and unemployment.<sup>5</sup> Consequently, despite progress,<sup>6</sup> further advances that improve outcomes are urgently required.<sup>7</sup>

Multi-stakeholder processes that prioritize research questions are a method of accelerating progress, by focusing activity and investment on key questions.<sup>8–10</sup> Fundamental to their success is the selection of the questions; the key uncertainties that if answered, will increase our knowledge and have the potential to change care. Such prioritization requires close engagement with front-line users; both professionals working with the disease, but also individuals living with it.<sup>11</sup>

Named after Dr. James Lind, reportedly the first clinician to undertake a randomized controlled trial, the James Lind Alliance (JLA) initiative was founded to support just this; research prioritization by front-line professionals and those with “lived experience.”<sup>12–14</sup> Since its inception in 2004, the JLA has refined its methodology and directly supported over 100 processes.

In this Global Spine Journal Special Edition, we share our JLA Priority Setting Partnership for DCM, conducted as part of the AO Spine RECODE-DCM ([aospine.org/recode](https://aospine.org/recode)) initiative, to increase efficiency and accelerate advances in DCM research.<sup>10</sup>

This extraordinary process, involving 429 individuals from 68 different countries was led by the AO Spine Knowledge Forum Spinal Cord Injury, a focused group of international spinal cord injury experts acting on behalf of AO Spine. It has

captured perspectives from 17 different healthcare professions, but also people with lived experience through our partnership with Myelopathy.org (DCM Charity). A total of 3404 research ideas were submitted, distilled into 74 unanswered summary questions and prioritized by consensus, across stakeholder groups into a Top 10 (Table 1).

These priorities extend beyond current research activity,<sup>15</sup> highlighting early-diagnosis, rehabilitation, long-term care, pre-clinical science, health economics, awareness and education. In particular, prioritization of education and awareness, represent the clear value for involving people living with the condition: (1) These emerged as their number 1 priority but were only ranked 25th by other healthcare professionals and 45th by surgeons initially. (2) A research question on education and awareness has never previously been a research priority in DCM, which arguably has been driven by the surgical community to date.

Identifying the top research priorities was one challenge, but ensuring they are disseminated and answered is the challenge to come. With this special edition, we aim to communicate the top research priorities that are based on robust methodology

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**Table 1.** AO Spine RECODE-DCM—Top 10 Research Priorities for Degenerative Cervical Myelopathy.<sup>a</sup>

No.	Priority	Description	Webpage link
1.	Raising Awareness	What strategies can increase awareness and understanding of DCM among healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?	<a href="https://aospine.org/recode/raising-awareness">aospine.org/recode/raising-awareness</a>
2.	Natural History	What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?	<a href="https://aospine.org/recode/natural-history">aospine.org/recode/natural-history</a>
3.	Diagnostic Criteria	What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the assessment of DCM?	<a href="https://aospine.org/recode/diagnostic-criteria">aospine.org/recode/diagnostic-criteria</a>
4.	Assessment and Monitoring	What assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?	<a href="https://aospine.org/recode/assessment-and-monitoring">aospine.org/recode/assessment-and-monitoring</a>
5.	Biological Basis	What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?	<a href="https://aospine.org/recode/biological-basis">aospine.org/recode/biological-basis</a>
6.	Perioperative Rehabilitation	What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?	<a href="https://aospine.org/recode/rehabilitation">aospine.org/recode/rehabilitation</a>
7.	Novel Therapies	Can novel therapies, including stem-cell, gene, pharmacological and neuroprotective therapies, improve the health and wellbeing of people living with DCM and slow down disease progression?	<a href="https://aospine.org/recode/novel-therapies">aospine.org/recode/novel-therapies</a>
8.	Socio-economic Impact	What is the socio-economic impact of DCM? ( <i>The financial impact of living with DCM to the individual, their supporters and society as a whole.</i> )	<a href="https://aospine.org/recode/socio-economic-impact">aospine.org/recode/socio-economic-impact</a>
9.	Imaging and Electrophysiology	What is the role of dynamic or novel imaging techniques and neurophysiology in the assessment of DCM?	<a href="https://aospine.org/recode/imaging-techniques">aospine.org/recode/imaging-techniques</a>
10.	Individualizing Surgery	Are there clinical and imaging factors that can help a surgeon select who should undergo surgical decompression in the setting of DCM? At what stage of the disease is surgery the preferred management strategy?	<a href="https://aospine.org/recode/individualizing-surgery">aospine.org/recode/individualizing-surgery</a>

<sup>a</sup>Further supporting information behind their prioritization is available from dedicated webpages. This includes the AO Spine RECODE-DCM Top 10 PODCAST series.

and involved a diverse community that delivered them. We also seek to contextualize their individual significance and potential research directions in dedicated narrative reviews. We hope this edition can inspire current and future researchers, and provide a basis for funders to develop a better understanding and more focused investment in DCM. We also hope that the clarity of the research priorities will enable funders to increase overall investment into this field. This is required to advance knowledge and address the large unmet clinical needs of people with DCM.

We thank all those that have contributed to AO Spine RECODE-DCM and the identification of the top research priorities. We now call upon the global research community to acknowledge these by directing their attention and resources to addressing them, embracing the notion that by focusing on the issues that are most compelling, the community can accelerate progress toward improving outcomes for this major (yet under-appreciated) health problem.

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