



## COMMENTARY

# Thinking Differently and Working Together: An Invitation for Collective Action in Degenerative Cervical Myelopathy - RECODE-DCM

Aref-Ali Gharooni, MD , Benjamin M. Davies, MD \*<sup>1</sup>

Academic Neurosurgery Unit, Department of Clinical Neurosciences, University of Cambridge, Cambridge, UK

**Keywords:** Degenerative cervical myelopathy, Spinal cord injury, Research, Education

Degenerative Cervical Myelopathy (DCM) represents a significant burden within spine care, affecting an estimated 5% of individuals over the age of 40. Despite its rising prevalence and devastating impact, DCM has often been overlooked in both research and clinical practice receiving <\$50m global research funding since 1995 [1, 2].

In 2019, we launched RECODE-DCM with the support of AO-Spine to define top research priorities involving multiple stakeholders including patients, carers, and healthcare professionals, to establish a core minimum dataset for clinical studies in DCM and solidify a standardized definition and index term for this condition. This aimed to address key inefficiencies that we saw within our field, to ensure globally we could work more effectively and efficiently together.

Five years on, we have met those objectives; we have selected (and defined) the term “Degenerative Cervical Myelopathy” [3], we have minimum dataset for research [4] and we have a list of the top ten research priorities [5]. But by working together and thinking differently, we have been able to go further.

RECODE-DCM was a series of global consensus processes. By virtue of bringing together a global and multistakeholder community, passionate and invested in improving care for DCM – totally unique – we have seen new ideas emerge and new research

directions. For example, recognising the limitations of a doctrine that DCM is a disease of compression, and instead conceptualising DCM as a function of Mechanical Loading, Vulnerability and Time [6].

What started as a defined project, has become a diverse community, with representation from 68 countries and 17 different healthcare disciplines. This community continues to work to change outcomes, a community that is expanding and you could be part of.

RECODE-DCM is now hosted by [Myelopathy.org](https://myelopathy.org), a global charity aiming to improve outcomes for those with DCM. Research projects are led by global working groups called incubators. Currently there are four incubators:

- (1) Education: How can we improve professional awareness of DCM, and accelerate diagnosis?
- (2) Natural History: How does DCM evolve from Asymptomatic Spinal Cord Compression?
- (3) Diagnostic Criteria: What are the symptoms and/or signs that should prompt MRI Assessment for DCM, and a diagnosis of DCM?
- (4) Peri-Operative Care: Enhanced Recovery After Surgery Guidelines for DCM

Moreover RECODE-DCM allows for the formation of additional incubators tailored to emerging needs,

Received 10 April 2024; accepted 13 April 2024.  
Available online 21 June 2024

\* Corresponding author at: Academic Neurosurgery Unit, Department of Clinical Neurosciences, University of Cambridge, Cambridge, UK.  
E-mail address: [bd375@cam.ac.uk](mailto:bd375@cam.ac.uk) (B. M. Davies).

<sup>1</sup> Co-Founder and Director of [Myelopathy.org](https://myelopathy.org)  
Online ISSN: 2974-4822; Print ISSN: 2974-4814; <https://www.advancedspinej.org>

<https://doi.org/10.57055/2974-4822.1294>

2974-4822/© 2024 Egyptian Spine Association (ESA).



and addressing other key research priorities, ensuring adaptability and relevance in an ever-evolving landscape.

There is still a long way to go and there is a role for everyone, of any expertise or background; whether it is conducting research, teaching or fundraising: progress for DCM starts by working together and thinking differently about this condition.

Through diverse collaborative endeavours and shared insights, we can drive applied research, refine clinical practice, and ultimately, improve outcomes for individuals grappling with DCM. We are working to end moderate to severe disability in DCM; are you ready to be part of this journey?

We invite colleagues from around the world who are interested in this field to get involved. Further information on current projects and how to participate can be found on [Myelopathy.org](https://myelopathy.org) [7] or *AO Spine* [8].

### Ethics information

The article does not contain information about medical device(s)/drug(s).

### Author declaration of funding statement

No funds were received in support of this work.

### Conflict of interest

The authors report no conflicts of interest.

## References

- [1] Bestwick H, Teh JQ, Mowforth O, Grodzinski B, Kotter M, Davies B. Existing funding sources in degenerative cervical myelopathy research: scoping review. *Interact J Med Res* 2022;11:e36194. <https://doi.org/10.2196/36194>.
- [2] Davies BM, Mowforth O, Wood H, Karimi Z, Sadler I, Tetreault L, et al. Improving awareness could transform outcomes in degenerative cervical myelopathy [AO spine RECODE-DCM research priority number 1]. *Global Spine J* 2022;12. <https://doi.org/10.1177/21925682211050927>.
- [3] Davies BM, Khan DZ, Barzangi K, Ali A, Mowforth OD, Nouri A, et al. We choose to call it 'degenerative cervical myelopathy': findings of AO spine RECODE-DCM, an international and multi-stakeholder partnership to agree a standard unifying term and definition for a disease. *Global Spine J* 2024;14:503-12. <https://doi.org/10.1177/2192568221111780>.
- [4] Myelopathy.org. DCM Minimum dataset n.d. <https://myelopathy.org/minimum-dataset/> (accessed March 25, 2024).
- [5] Davies BM, Kwon BK, Fehlings MG, Kotter MRN. AO spine RECODE-DCM: why prioritize research in degenerative cervical myelopathy? *Global Spine J* 2022;12:5S. <https://doi.org/10.1177/21925682211035379>.
- [6] Davies BM, Mowforth O, Gharooni AA, Tetreault L, Nouri A, Dhillon RS, et al. A new framework for investigating the biological basis of degenerative cervical myelopathy [AO spine RECODE-DCM research priority number 5]: mechanical stress, vulnerability and time. *Global Spine J* 2022;12:78S. <https://doi.org/10.1177/21925682211057546>.
- [7] Myelopathy.org. Myelopathy.org - Join an Incubator n.d. <https://myelopathy.org/join-an-incubator/> (accessed March 18, 2024).
- [8] AO Foundation. AO Spine RECODE-DCM n.d. <https://www.aofoundation.org/spine/research/recode-dcm> (accessed March 18, 2024).