

# AO Spine RECODE-DCM Ambassadors



- Degenerative Cervical Myelopathy (DCM) is the number one cause of spinal cord impairment globally, affecting as many as 2 % of adults.
- Despite treatment, less than 5 % of people with DCM will make a full recovery, while most people will have life-long disability and some of the lowest quality of life scores for long-term conditions.
- Research advances are urgently required.

AO Spine **RE**search Objectives and **CO**mmon **Data Elements** for DCM (**RECODE-DCM**) is an international initiative to create a research toolkit that helps accelerate knowledge discovery and improve outcomes in DCM.



**Mark Kotter**

Principal Investigator, AO Spine  
Knowledge Forum SCI Member

“AO Spine RECODE-DCM has identified the research priorities. Now, we need the research community to answer these questions, and advance patient care and outcomes.”



**Benjamin Davies**

Co-principal Investigator, AO Spine  
Knowledge Forum SCI Member

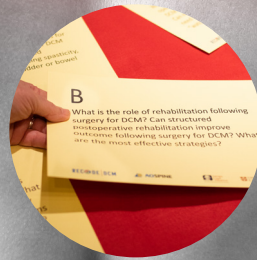
“These priorities have shown DCM cannot be solved by a surgeon alone. I hope we can use this platform to kindle interest in DCM more broadly and bring about progress faster.”

# AO Spine RECODE-DCM

AO Spine RECODE-DCM produces recommendations that can help researchers work faster and more efficiently to answer questions about DCM and promote excellence in patient care and outcomes.

AO Spine RECODE-DCM established the top 10 research priorities for DCM through a global consensus process thanks to the insights of surgeons, other health professionals, and people living with DCM.

We need your help to make sure these questions get answered!





# AO Spine RECODE-DCM Ambassadors

**Leaders and experts championing chosen research priorities as part of the AO Spine RECODE-DCM Knowledge Translation and Implementation Initiative.\***

## Why get involved?

- Support leaders and experts in raising awareness and understanding of DCM among clinicians, other health professionals, and the public.
- Promote commitment from leading authorities worldwide and focus research on specific research priorities.
- Be part of a global research initiative to make a difference to research and people living with DCM.

Each research priority will have a panel of Ambassadors, including clinicians, other health professionals, and people with DCM.

\* Knowledge Translation is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of people, provide more effective health services and products and strengthen the health care system.(CIHR 2020)



# Top Ten Research Priorities

1. What strategies can increase awareness and understanding of DCM amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?
2. 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?
3. What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the assessment of DCM?
4. 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?
5. What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?
6. 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?
7. 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?
8. What is the socio-economic impact of DCM? (The financial impact of living with DCM to the individual, their supporters and society as a whole).
9. What is the role of dynamic or novel imaging techniques and neurophysiology in the assessment of DCM?
10. 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?

# The Role of an AO Spine RECODE-DCM Ambassador

## AO Spine RECODE-DCM Ambassadors

- represent a RECODE-DCM research priority of your choice;
- promote the research questions actively for uptake
  - through personal networks,
  - at conferences and networking events,
  - by supporting webinars organized by AO Spine;
- seek avenues of funding and approach potential partners;
- encourage communication and knowledge exchange;
- get involved in drafting a systematic review describing the meaning of the priority, existing research and evidence related to it, and possible research questions for sub studies;
- respond directly to newly published research, e.g. through correspondence with the author/letter to the editor; and liaise with AO Spine RECODE-DCM Steering group and Management group.



# Ambassadorial team

## Who are on the Ambassadorial team?

- Surgeons
- Other health professionals involved in the care of people with DCM
- People with DCM or their representatives
- Communications specialists
- Researchers
- Admin and project support staff

The Knowledge Translation and Implementation process is overseen and supported by AO Spine and AO Spine Knowledge Forum Spinal Cord Injury, in collaboration with University of Cambridge, Myelopathy.org, and the James Lind Alliance.



# Why I became an Ambassador



**James Harrop**

Neurosurgeon, USA

"I have learned that we can see a different perspective by listening to our patients.

I firmly believe that answering these questions can accelerate progress and advance outcomes in DCM."



**Sukhvinder Kalsi-Ryan**

Clinician Scientist, Canada

"AO Spine RECODE-DCM has listened to professionals and patients of all backgrounds and set the direction for future cervical myelopathy research.

I am proud to be part of this change."



**Ricardo Rodrigues-Pinto**

Surgeon, Portugal

"I am inspired by the commitment and passion of the AO Spine RECODE-DCM group to champion research that can improve outcomes."



**Ellen Sarewitz**

Person living with this condition, UK

"This initiative is more than a list of research priorities; it's the platform to educate society and address a disabling and hidden epidemic."



# Why I became an Ambassador



**James Milligan**

Family Medicine  
Physician, Canada

“Changing care is about asking and answering the right questions. You can only get this from listening to the people living and working with the disease.”



**Michelle Starkey**

Scientist, UK

“I became an ambassador because I recognize that unless communities respond and target these questions, we will miss an incredible opportunity to accelerate progress.”



**Paige Howard**

Person living with  
this condition, USA

“My life was turned upside down by DCM. I am motivated to ensure this doesn't happen to others in the future.”



**Iwan Sadler**

Person living with  
this condition, UK

“Our community is full of capable and interested researchers. I believe these priorities can be the catalyst they need to advance outcomes quickly.”



# How to get involved?

If you would like to learn more about AO Spine RECODE-DCM, please visit [www.aospine.org/recode](http://www.aospine.org/recode).

If you would like to get involved as an Ambassador contact the AO Spine Knowledge Forum Spinal Cord Injury research project manager, Olesja Hazenbiller  
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