RECODE DCM

Newsletter, 20 December 2021

Throughout 2021 in the AO Spine RECODE-DCM community, we have been advancing our mission to accelerate knowledge discovery and improve outcomes for Degenerative Cervical Myelopathy. This holiday season, we hope that the 12 days of Christmas bring you peace and an opportunity to reflect on 12 of our milestone achievements and our New Year's resolutions for 2022.

12 **Standardizing studies:** In June 2022 at the Global Spine Congress in Las Vegas, the RECODE-DCM group will hold a consensus meeting to determine the Core Measurement Set. By determining which assessment scales to use in DCM research, we will standardise studies to accelerate progress.

11 **Celebrating prizewinning research:** In 2022, Myelopathy.org, the world's only charity dedicated to DCM, will announce its annual research prize for best piece of research aligned with one of the Top Ten priorities. Will you be in the running?

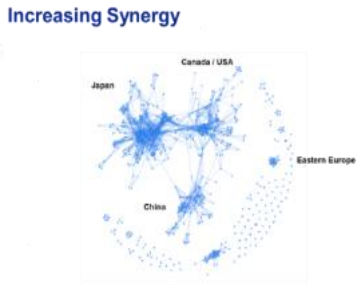
10 **Creating a standard code:** In mid-2022, we will make a formal submission to the World Health Organization to develop an ICD code for DCM.

9 **Guidebook for innovation:** In February 2022, we will launch the special focus issue of *Global Spine Journal*. In this milestone publication, experts will contextualise the Top Ten Research Priorities, to stimulate the research field to solve the top questions that are critical for improving outcomes in DCM.

8 **Disseminating the Top Ten:** In January 2022, we will release our citation guidance for the Top Ten Research Priorities, to increase their traction and raise their profile globally.



Knowledge translation involves communicating valuable information between the right people—the agents of change—to ensure meaningful engagement and impact.





"Research often does not cross borders," says Manabu Ito, orthopedic spine surgeon from Japan and an Ambassador for the Natural History incubator. "When we work together, we can progress faster and more effectively for our patients."

7 **Evolving incubators:** In 2021, we launched incubators focusing on three of the Research Priorities: Natural History, Diagnostic Criteria, and Peri-Operative Rehabilitation. They will enhance synergy between international research groups, focus knowledge discovery, and translate knowledge across disciplines.



L to R: Oliver Mowforth (a junior doctor in Cambridge who has just started his residency), with Principal Investigator Mark Kotter and co-Principal Investigator Benjamin Davies. Their festive mood is in recognition of Oliver's new academic training appointment, reflecting the positive energy and expertise he has invested in RECODE-DCM.

6 **Widening our network:** Throughout 2021, we have diversified our community, inviting junior doctors to join forces with world-renowned thought leaders, bringing aboard people who care for loved ones with DCM alongside surgeons and allied health specialists, and summoning colleagues from the traumatic SCI and stroke field. This sharing of perspectives ignites positivity and enthusiasm.

5 **Translating knowledge:** Critical to the ethos of RECODE-DCM, our knowledge translation plan is gathering speed. Our hardworking 'agents of change' extend our multidisciplinary network, bridging the gap between the research bench and the day-to-day function of people living with DCM.

4 **Broadcasting voices of DCM:** At the close of 2020, we examined the Research Priorities in our podcast series, 'Myelopathy Matters'. In the first two months of its release, the podcast achieved over 10,000 listens. This extraordinary response surpasses the outreach of most scientific papers, forging new lines of communication.

3 **Measuring what matters:** Also in 2020, we agreed the Minimum Data Set (soon to be published), to ensure that studies cover the full scope of the disease and are comparable going forward.

2 **Clarifying nomenclature:** In October 2020, we agreed the Definition and Index Term, to inform international classifications and disease codes. Now, we can integrate research findings under one index term and speak the same language across different medical specialities.

1 **Prioritizing for people with DCM:** At a Priority-Setting Partnership in November 2019, facilitated by the James Lind Alliance, we set the Top Ten Research Priorities – the questions that matter most to the people who live with DCM.



We send everybody in the community our heartfelt gratitude for all the energy, passion and resolve that you bring to our mission. With your sustained input, our initiative will continue to snowball in 2022. We wish you a reinvigorating festive season!

Benjamin Davies, co-Principal Investigator, AO Spine RECODE-DCM