

# Degenerative Cervical Myelopathy Awareness in Primary Care: A UK National Cross-Sectional Survey of General Practitioners

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### Abstract

**Background:** Degenerative cervical myelopathy (DCM) is a progressive neurological condition, characterised by spinal cord injury secondary to degenerative changes in the spine. Misdiagnosis in primary care forms part of a complex picture leading to an average diagnostic delay of 2 years. This leads to potentially preventable and permanent disability. A lack of awareness secondary to deficits in postgraduate educational may contribute to these delays.

**Objective:** The aim of this study was to assess the awareness of DCM in the setting of general practice.

**Methods:** General practitioners (GPs) completed a quantitative web-based cross-sectional questionnaire. The 17-item questionnaire captured data regarding demographics, subjective awareness, and objective knowledge. The questionnaire was disseminated via professional networks, including via practice managers and senior practice partners. Incentivisation was provided via a bespoke DCM fact sheet for those that completed the survey.

**Results:** A total of 54 GPs representing all 4 UK nations responded to the survey. GPs most commonly self-assessed that they had 'Limited Awareness' of DCM (n=24, 51.1%). GPs felt most commonly 'Moderately Able' to recognise a case of DCM (n=21, 45.65%). In total 13.0% (n=6) of respondents reported that they would not be at all able to recognise a patient with DCM. Respondents most commonly reported that they were 'Moderately Confident' in their ability to triage a patient with DCM (n=19, 41.30%). A quarter of respondents reported no prior introduction to DCM throughout their medical training (n=13, 24.53%). The mean score for knowledge-based questions was  $42.6 \pm 3.96$  % with the lowest performance observed in patient demographic and clinical recognition items.

**Conclusions:** GPs lack confidence in the recognition and management of DCM. These findings are consistent with the diagnostic delays previously described in the literature at the primary care level. Further work to develop and implement educational interventions to GP practices is a crucial step to improving patient outcomes in DCM.

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# **Original Manuscript**

#### **Original Article**

# Degenerative Cervical Myelopathy Awareness in Primary Care: A UK National Cross-Sectional Survey of General Practitioners

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**Key words:** cervical spine; degeneration; general practice; myelopathy; neurology; neurosurgery; medical education

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Abstract

#### Introduction

Degenerative cervical myelopathy (DCM) is a progressive neurological condition, characterised by spinal cord injury secondary to degenerative changes in the spine. Misdiagnosis in primary care forms part of a complex picture leading to an average diagnostic delay of 2 years. This leads to

potentially preventable and permanent disability. A lack of awareness secondary to deficits in postgraduate educational may contribute to these delays. The aim of this study was to assess the awareness of DCM in the setting of general practice.

#### Methods

General practitioners (GPs) completed a quantitative web-based cross-sectional questionnaire. The 17-item questionnaire captured data regarding demographics, subjective awareness, and objective knowledge. The questionnaire was disseminated via professional networks, including via practice managers and senior practice partners. Incentivisation was provided via a bespoke DCM fact sheet for those that completed the survey.

#### Results

A total of 54 GPs representing all 4 UK nations responded to the survey. GPs most commonly self-assessed that they had 'Limited Awareness' of DCM (n=24, 51.1%). GPs felt most commonly 'Moderately Able' to recognise a case of DCM (n=21, 45.65%). In total 13.0% (n=6) of respondents reported that they would not be at all able to recognise a patient with DCM. Respondents most commonly reported that they were 'Moderately Confident' in their ability to triage a patient with DCM (n=19, 41.30%). A quarter of respondents reported no prior introduction to DCM throughout their medical training (n=13, 24.53%). The mean score for knowledge-based questions was  $42.6 \pm 3.96$ % with the lowest performance observed in patient demographic and clinical recognition items.

#### Conclusion

GPs lack confidence in the recognition and management of DCM. These findings are consistent with the diagnostic delays previously described in the literature at the primary care level. Further work to develop and implement educational interventions to GP practices is a crucial step to improving patient outcomes in DCM.

#### Introduction

Degenerative cervical myelopathy (DCM) is a common progressive neurological condition, characterised by compression of the cervical spinal cord secondary to degenerative changes in the spine [1–4]. Prevalence in the over 40s is estimated to be 5%, making it the most common cause of spinal cord pathology worldwide [1,2,5,6]. Disease progression has profound impacts upon the quality of life of patients [7–10], resulting in pain, functional neurological decline and disability.

The nature of the pathology lends itself to favourable outcomes with early diagnosis. Whilst existing damage is irreversible, surgery has been demonstrated to halt progression [11,12]. Despite the benefits of surgical intervention, an average diagnostic delay of 2 years has been observed, typically requiring 5 clinic appointments. Misdiagnosis in primary care plays a part in the complex picture leading to delays in the patient pathway [13,14].

Misdiagnosis likely arises due to a lack of awareness, driven by inconsistent terminology [15], similarity with other presentations, and low levels of research activity. Most significantly, recent studies have reported deficient teaching and representation of DCM in medical education curricula [16]. It may be speculated that poor education at medical schools translates to a lack of awareness of DCM amongst primary care physicians.

To our knowledge, no study has yet characterised the awareness of DCM in primary care. The objective of this study was therefore to assess awareness of DCM in primary care, specifically amongst general practitioners (GPs) in the UK. The aim is to identify knowledge gaps which may inform initiatives to improve postgraduate knowledge, ultimately improving efficiency of diagnosis and patient outcomes. Improving DCM education is also an important component of the number one research priority of the AO Spine RECODE-DCM international research priority setting initiative: improving awareness [15].

#### **Methods**

The survey was designed following the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [17].

#### **Study Partners**

Myelopathy.org

Myelopathy.org is a global charity with the primary objective of advancing the health and well-being of individuals affected by DCM. The charity places a strong emphasis on enhancing medical education to effectively combat the prevailing challenges of delayed or overlooked diagnosis. This research is a component of a broader initiative that seeks to assess the level of DCM knowledge and awareness among medical practitioners and create strategies to enhance it.

Student Society of Myelopathy.org

The student society of myelopathy.org works to promote the goals of myelopathy.org. It coordinates teaching, student essay prizes, and projects to promote the awareness and improve the treatment of DCM. It has designed and initiated this study to help serve these goals.

#### **Survey Design**

It was decided that the most efficient manner to cross-sectionally capture the knowledge and awareness of GPs regarding DCM across the UK was an electronic survey. The survey entailed 2 parts. Part 1 obtained information regarding the demographics of practitioners in addition to their previous experience of the condition. Part 2 provided a multifaceted assessment. Firstly, the knowledge that would be required of a practitioner to successfully recognise a potential case of DCM was probed. Questions therein related to symptomology and signs at presentation. Furthermore, part 2 evaluated a participant's ability to ensure prompt treatment by capturing knowledge of appropriate means of referral and investigation. Additional foci included questions regarding patient experience of the disease, patient demographics, and practitioner's subjective assessment of their knowledge.

The survey was compiled using an iterative approach. Questions were developed with input from a GP (ES) and academic neurosurgeons with a subspecialist interest in DCM (OM, BD). Part 1 was refined to the point at which it was felt that enough practitioner related demographic information was obtained to allow analysis of potential confounders. Similarly, part 2 was developed to a point at which it assessed the fundamental knowledge required by a general practitioner to provide appropriate primary care management to a patient with DCM. This resulted in a 17-item questionnaire (Appendix 1).

## **Survey Piloting**

The piloting group consisted of GPs who were not involved in study design. It was highlighted during this phase that ambiguity arose in a question regarding referral due to differences across regions regarding musculoskeletal referral pathway (Appendix 1). The question was subsequently updated to remove ambiguity before wider dissemination. It was reported that the format was readily accessible on both desktop and laptop. Relevant responses from this pilot group were included in the final analysis where question items were deemed appropriate for the final survey dissemination.

### **Survey Administration**

The survey was hosted by Momentive on their Survey Monkey platform (San Mateo, CA), a commercial online survey platform. The platform offers both desktop and mobile formatting making the survey readily accessible.

The survey contained 17 items, with the final item (being optional) requesting contact details for those who wished to receive a fact sheet regarding DCM for their future practice.

#### Dissemination

To achieve widespread dissemination of the survey across the UK, appropriate professional networks were approached to facilitate electronic distribution of the survey. Practice managers and senior partners, who had no affiliation with the survey, disseminated the survey throughout their networks. Whilst prompted to advertise the survey on one occasion, it was left to the practice managers and senior partners discretion as to whether follow up prompts were administered.

Professional networks were engaged in a manner to capture representation of general practitioners across a wide geographical base. Representation of general practitioners was obtained from all four nations. Responses were collected from the period of September 2022 to July 2023.

As an incentive to complete the questionnaire, participants were offered a fact sheet containing the key knowledge required at the level of primary care about the condition, on completion of the survey. It was felt that this was an appropriate incentive which avoided compromising the integrity of the survey whilst also helping to achieve one of the goals of Myelopathy.org in improving awareness and

treatment of DCM. This agreed by the study management group and the research ethics committee.

### **Eligibility and Representation**

Any general practitioner working within the UK was eligible to complete the survey. We aimed to achieve representation of all 4 UK nations.

### **Ethical Approval**

Ethical approval was granted by the University of Cambridge Psychology Research Ethics Committee (Application No: PRE.2022.115).

### **Consent and Confidentiality**

The participant information sheet highlighted the importance, objectives, and voluntary aspect of participation, whilst being cautious in selecting background information about DCM to avoid biasing responses for the knowledge-based survey questions. To ensure both anonymity and confidentiality, participants created a distinctive identifier using specific details from their mother's maiden name and mobile phone number, enabling the potential linkage of future surveys by the same participant.

### **Data Security**

The data remained solely on the secure, online Survey Monkey (Momentive, San Mateo, CA) platform until the survey closed. Subsequently, the survey data was transferred from the Survey Monkey platform to a password-protected computer, using an Excel spreadsheet (Microsoft, Seattle, WA). Access to this data was strictly limited to the immediate research team on an as-needed basis. Once the data analysis was completed, any unnecessary data was permanently deleted. Importantly, no participant-identifiable data was collected or stored.

#### **Statistical Analysis**

Data analysis and visualisation were performed using R version 4.3.1 (R Core Team, Vienna, Austria) and RStudio Version 2023.06.1 (RStudio Team, Vienna, Austria).

Fisher's Exact test was utilised to assess for associations between respondent characteristics and survey responses. This was used in place of a chi-squared statistic due to the small sample size of the data. Where comparisons between respondent characteristics and responses expressed quantitatively as proportions of correct answers were sought, the Kruskall-Wallis ANOVA was employed, as the data were non-parametric. Errors reported are the standard error of the mean.

#### **Results**

#### **Summary of Respondent Characteristics**

Our survey captured the responses of 54 GPs, representing all four nations of the United Kingdom (England 29.6%, Northern Ireland 64.8%, Scotland 3.7%, Wales 1.9%). Responses came mostly from experienced GPs: 9 (16.7%) were still in training, 6 (11.1%) were under 5 years post-training, 7 (13.0%) were 5-10 years post-training, 20 (37.0%) were 11-20 years post-training, and 12 (22.2%) were more than 20 years post-training. The full dataset can be found in Appendix 2.

### **Training and Exposure**

The stage of training at which respondents were first introduced to DCM varied. Respondents were most commonly introduced to DCM in medical school (n=16, 30.2%), whilst 43.4% (n=23) reported being introduced to DCM during training after medical school (Figure 1). A quarter of respondents reported no prior introduction to DCM throughout their medical training (n=13, 24.5%). Most GPs

(n=27, 51.0%) reported at least 1 encounter with suspected DCM per month (Figure 2). In total, 49.0% (n=26) respondents reported encountering zero patients per month with suspected DCM.

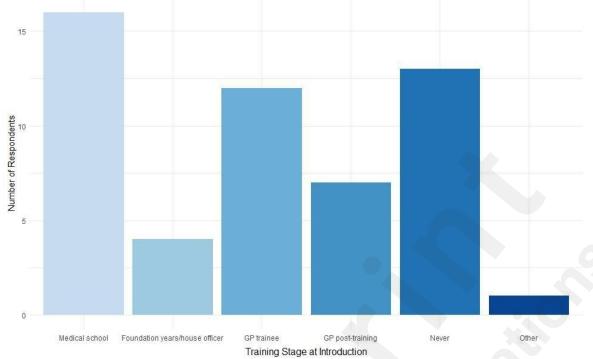


Figure 1. GP responses to the question 'At which stage of your training were you introduced to DCM, also historically known as cervical spondylitic myelopathy?'.

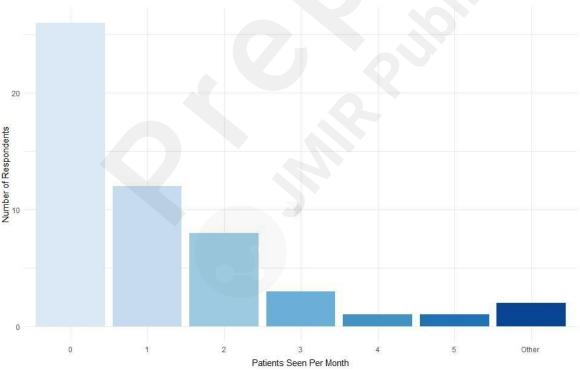


Figure 2. GP responses to the question 'Approximately how many patients with suspected DCM do you encounter, per month, in clinical practice?'.

#### **Subjective Awareness**

Survey respondents were asked to subjectively assess their levels of awareness of DCM. The most common response was 'Limited Awareness' (n=24, 51.0%, Figure 3). A total of 3 respondents

reported 'No Awareness' (6.4%). No respondents reported having an 'Excellent Awareness' of the condition. There was no significant association between the number of years of training of respondents and their subjectively rated awareness of DCM (P = .15).

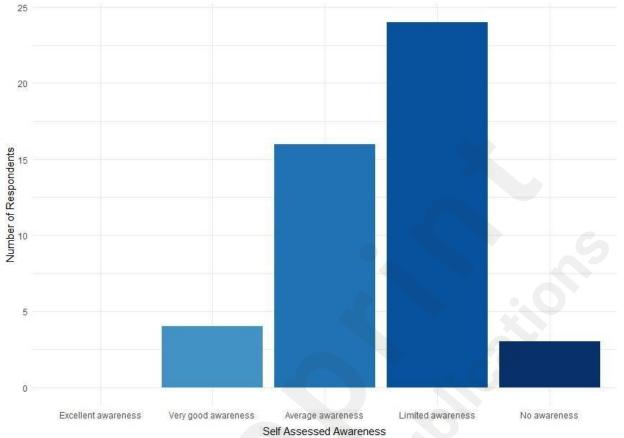


Figure 3. GP responses to the question 'How would you currently rate your awareness of myelopathy/degenerative cervical myelopathy (DCM)?'.

Respondents were also asked to subjectively rate their ability to recognise DCM. The most common response was 'Moderately Able' (n=21, 45.7%, Figure 4). No respondents felt that they were 'Extremely Able', however 13.0% (n=6) reported that they would be 'Not at all Able' to recognise a patient with DCM.

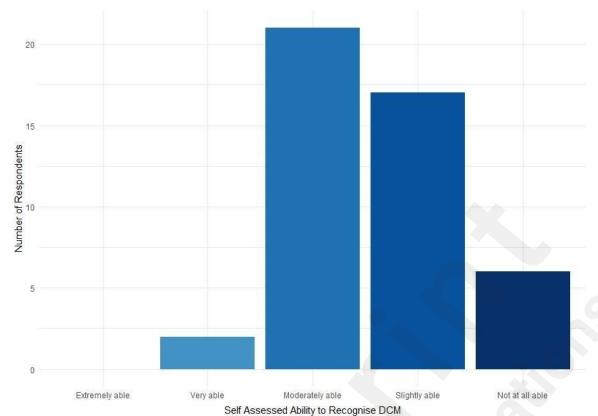


Figure 4. GP responses to the question 'How do you currently rate your ability to recognise myelopathy/degenerative cervical myelopathy (DCM)?'.

Finally, respondents self-assessed their confidence in triaging a patient with DCM. Few respondents felt 'Very Confident' (n=4, 8.7%) or 'Extremely Confident' (n=1, 2.2%) in triage (Figure 5). Respondents most commonly reported that they were 'Moderately Confident' in their ability to triage a patient with DCM (n=19, 41.3%). There was no significant association between the number of years of training of respondents and their subjectively rated ability to recognise DCM (P = .53).

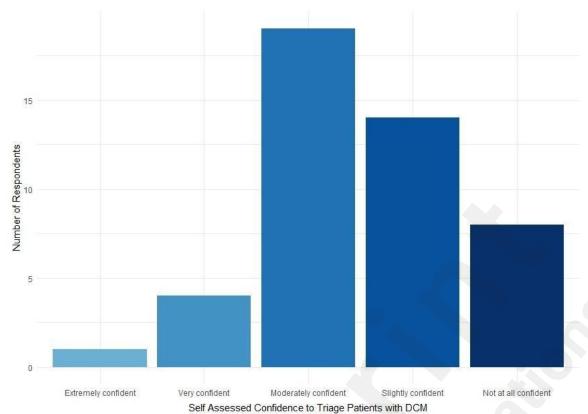


Figure 5. GP responses to the question 'If you suspect a case of DCM, how confident are you currently at triaging that patient (i.e., knowing where to refer them and how quickly)?'.

### **Objective Awareness**

When asked 6 objective questions to assess knowledge of DCM, the mean score of respondents was 42.6  $\pm$  4.0 %. There was no statistically significant correlation between performance and years of training ( $\chi$ 2=5.6, P =.23, Figure 6).

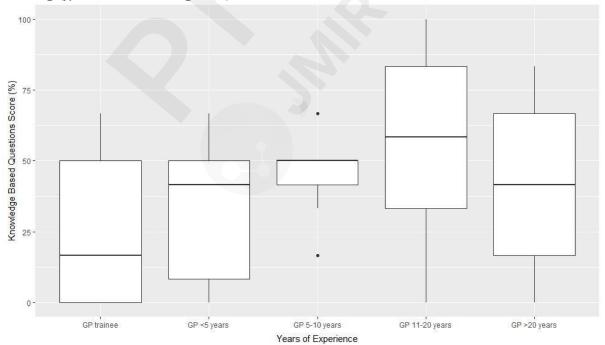


Figure 6. GP performance in knowledge-based questions stratified by years of experience

Performance varied by question item and topic area. The lowest performance was observed in question items relating to patient demographics and clinical recognition. A total of 19.15% (n=9) correctly identified the prevalence of DCM in those aged over 40, whilst 50% of respondents (n=21) answered the correct clinical sign to differentiate DCM from carpal tunnel syndrome (Appendix 2). In contrast, 78.26% of respondents (n=36) correctly identified the most important modality of imaging to diagnose DCM. Furthermore, 73.81% of respondents (n=31) correctly identified that referral to neurosurgery would be the most appropriate form of triage for a patient who has been diagnosed with degenerative cervical myelopathy.

#### Discussion

One of the major challenges currently facing people with DCM is delayed diagnosis. For a progressive, largely irreversible condition with treatment available that can halt progression, early diagnosis and specialist care is fundamentally important for good patient outcomes [18]. Misdiagnosis is part of a complexed picture leading to delayed diagnosis [13]. Our findings suggest that a lack of awareness about DCM and a low ability to recognise the condition may contribute to misdiagnosis in primary care. GPs also reported a lack of training on DCM, with a substantial proportion of respondents reporting that they had not encountered DCM at any point in their training. Despite low confidence and awareness about DCM, respondents demonstrated a reasonable level of performance on questions related to disease management.

## **General Practitioners Report Difficulties in Recognising DCM**

A key finding from our survey was GPs low self-assessed ability to recognise a case of DCM. Only a small minority (n=2, 4.35%) felt they were 'Very Able' or 'Extremely Able' to recognise DCM, with 50% (n=23) feeling either 'Slightly Able' or 'Not Able at All' (Figure 4). This was reflected in the results of questionnaire items objectively assessing ability to recognise DCM. When asked to identify features of patient presentation that may differentiate DCM from carpal tunnel syndrome, only 50% of respondents responded correctly. These observations could not be explained by respondents' level of experience. Neither confidence in recognition nor performance in knowledge-based questions were statistically significantly correlated with the number of years of experience as a GP.

Previous work has detailed the pathway to definitive management of DCM, with delay secondary to misdiagnosis in primary care being a factor [13,19]. Of note, the most common diagnosis received was carpal tunnel syndrome [13]. We propose that this delay may be due to a lack of knowledge regarding the clinical presentation of DCM.

Prior gap analysis has demonstrated a deficiency in references to DCM in both educational curricula and study materials [20]. Our results corroborate these findings, with 24.53% (n=13) of respondents reporting never having been introduced to DCM at any point in their training (Figure 1). This large absence of education may be an underlying cause for the difficulties that GPs have expressed and demonstrated in this study.

It is of note that our respondents included GP trainees. Incomplete training from respondents introduces the potential to confound our results. However, of the respondents who reported having never been introduced to DCM, only 1 respondent (7.69%) was a trainee.

### General Practitioners Report Low Confidence in the Management of DCM

GPs did not feel confident in appropriately triaging patients with DCM. A total of 41 GPs (89.43%) felt at best 'Moderately Confident' in triage, whilst 8 (17.39%) felt 'Not Confident at All' (Figure 5). Despite low confidence, respondents performed comparatively well on questions relating to investigation and management of DCM, where 31 respondents (73.81%) correctly identified

appropriate modes of referral (Appendix 2).

This discrepancy between the confidence expressed by GPs to correctly triage patients, and their responses to knowledge-based questions may be explained by the cuing bias that single best answer style questions may introduce to applied medical knowledge assessments [21]. However, it is important to highlight that a large proportion of respondents (n=11, 26.19%) selected an inappropriate mode of referral which would lead to delays in management [19]. Moreover, the lack of DCM training reported by respondents may have left general practitioners feeling poorly equipped to provide appropriate management to patients with DCM.

### General Practitioners Underestimate Prevalence and Misdiagnosis of DCM

Most respondents answered incorrectly to both the prevalence of DCM (n=38, 80.85%) and the average time of diagnosis (n=30, 63.83%).

We believe that an underappreciation of the scale of the problem regarding the delayed diagnosis of DCM may disincentivise efforts amongst the GP community to address the issues identified. Additionally, an underestimate of the base-rate of disease amongst the general population may negatively affect probabilistic reasoning, leading to underdiagnosis [22,23]. Efforts to increase understanding of these issues are aligned with the number one research priority identified by the AO Spine RECODE-DCM initiative – *improving awareness* [15].

# Deficits in GP Confidence and Awareness May Reflect Broader Issues in Neurological Education

Diagnostic delay is not unique to DCM. Other neurological conditions, including dementia, amyotrophic lateral sclerosis and epilepsy face similar problems [24–26]. Although this is partially attributable to the insidious progression that characterises many neurological conditions, educational shortcomings have been well described in the literature [27,28].

The phenomenon of neurophobia is believed to be another one of the factors contributing to such shortcomings. This describes a disinclination of medical students and junior doctors to tackle the task of understanding neurological disease [29,30]. This may go some way to explain the consistent lack of confidence revealed from the results of our survey, even when related objective questions were answered more accurately.

Reviews of the literature have demonstrated that there is currently limited evidence regarding effective interventions for neurology education [31]. The development of a strong evidence base for effective interventions in neurology education of all levels would be of great value not just to the prognostics of DCM, but to neurological conditions as a whole.

#### **Limitations and Future Work**

To our knowledge, this is the first study that attempts to identify levels of confidence and awareness amongst GPs pertaining to DCM. Our survey relied partially on GPs' self-evaluation of their awareness of DCM, potentially introducing response and recall biases. To enhance the robustness of our findings and mitigate the effects of such bias, we incorporated an objective assessment of awareness into our survey.

Despite widespread dissemination with an appropriate incentive, recruitment of GPs proved a challenge, resulting in a relatively small sample size. Challenges in recruitment may be partially attributed to unprecedented clinical pressures facing GPs in the UK [32, 33]. This limitation restricts the generalisability of our findings to GPs across the UK and may introduce selection bias. Furthermore, whilst our survey successfully achieved representation from all nations in the UK, a significant proportion of this was from GPs based in Northern Ireland, which further limits the generalisability of our results.

Whilst our study highlights the relatively low awareness of DCM amongst GPs in the UK, future work should aim to validate our preliminary findings using a larger and more diverse sample of

primary care clinicians. Given our difficulty in attaining even UK wide representation, future studies may benefit from focusing on individual UK regions, allowing targeted use of resources in underrepresented areas.

Literature regarding GP awareness of DCM internationally is sparse. However, previous work suggests that lack of awareness exists in other health care systems in the global north [13]. International surveys may offer valuable insights and opportunities for learning from countries with a comparatively higher awareness of DCM.

Our results suggest a discrepancy between GPs confidence of primary care management of DCM and performance in objective assessments. To gain a deeper understanding of this phenomenon and the wider factors influencing DCM awareness in the primary care setting, it would be beneficial to supplement questionnaire data with qualitative research methods, including interviews and focus groups. These could be used to define the learning needs of the population.

This understanding provides a clear rationale for educational intervention at the primary care level. Such education must provide clarity and simplification to recognition and management of DCM. No diagnostic criteria currently exist for DCM. It is only recently that DCM was defined [34-35]. We plan to develop diagnostic criteria for DCM, following which we would reassess confidence and awareness of DCM. Considering the limitations in generalisability of this study and its cross-sectional nature, validation of such approaches may require focused assessment of GP awareness and confidence both before and after intervention.

Previous work has noted the significant difference between the neurological examination of specialists versus non specialists, with the former often targeting examination to rule out specific differentials [36-37]. A clear reference tool for GPs may aid prompt and streamlined referral onto secondary care, reducing subsequent disability [38-40]. This aligns with the number three research priority identified by the AO Spine RECODE-DCM initiative – *establishing diagnostic criteria for DCM* [38].

#### Conclusion

DCM is a rising health concern [41-42] for which GPs lack confidence in the recognition and management of DCM. This lack of awareness has clear implications for prompt diagnosis and referral onto specialist care. Addressing the education deficits highlighted by this study is an essential step to resolving these issues.

#### References

1. Nouri A, Tetreault L, Singh A, Karadimas SK, Fehlings MG. Degenerative Cervical Myelopathy: Epidemiology, Genetics, and Pathogenesis. Spine. 2015 Jun 15;40(12):E675-693. PMID: 25839387

- 2. Davies BM, Mowforth OD, Smith EK, Kotter MR. Degenerative cervical myelopathy. BMJ. 2018 Feb 22;360:k186. PMID: 29472200
- 3. 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. Glob Spine J. 2022 Feb;12(1 Suppl):78S-96S. PMID: 35174728
- 4. Grodzinski B, Durham R, Mowforth O, Stubbs D, Kotter MRN, Davies BM. The effect of ageing on presentation, management and outcomes in degenerative cervical myelopathy: a systematic review. Age Ageing. 2021 May 5;50(3):705–15. PMID: 33219816
- 5. Kovalova I, Kerkovsky M, Kadanka Z, Kadanka Z, Nemec M, Jurova B, et al. Prevalence and Imaging Characteristics of Nonmyelopathic and Myelopathic Spondylotic Cervical Cord Compression. Spine. 2016 Dec 15;41(24):1908–16. PMID: 27509189
- 6. Smith SS, Stewart ME, Davies BM, Kotter MRN. The Prevalence of Asymptomatic and Symptomatic Spinal Cord Compression on Magnetic Resonance Imaging: A Systematic Review and Meta-analysis. Glob Spine J. 2021 May;11(4):597–607. PMID: 32677521
- 7. Oh T, Lafage R, Lafage V, Protopsaltis T, Challier V, Shaffrey C, et al. Comparing Quality of Life in Cervical Spondylotic Myelopathy with Other Chronic Debilitating Diseases Using the Short Form Survey 36-Health Survey. World Neurosurg. 2017 Oct;106:699–706. PMID: 28065875
- 8. Davies B, Mowforth O, Sadler I, Aarabi B, Kwon B, Kurpad S, et al. Recovery priorities in degenerative cervical myelopathy: a cross-sectional survey of an international, online community of patients. BMJ Open. 2019 Oct 1;9(10):e031486. PMID: 31601597
- 9. Boerger T, Alsouhibani A, Mowforth O, Hamilton J, Lalkhen A, Davies BM, et al. Moving Beyond the Neck and Arm: The Pain Experience of People With Degenerative Cervical Myelopathy Who Have Pain. Glob Spine J. 2022 Sep;12(7):1434–42. PMID: 33626937
- 10. Hirayama Y, Mowforth OD, Davies BM, Kotter MRN. Determinants of quality of life in degenerative cervical myelopathy: a systematic review. Br J Neurosurg. 2023 Feb;37(1):71–81. PMID: 34791981
- 11. Fehlings MG, Wilson JR, Kopjar B, Yoon ST, Arnold PM, Massicotte EM, et al. Efficacy and safety of surgical decompression in patients with cervical spondylotic myelopathy: results of the AOSpine North America prospective multi-center study. J Bone Joint Surg Am. 2013 Sep 18;95(18):1651–8. PMID: 24048552
- 12. Fehlings MG, Ibrahim A, Tetreault L, Albanese V, Alvarado M, Arnold P, et al. A global perspective on the outcomes of surgical decompression in patients with cervical spondylotic myelopathy: results from the prospective multicenter AOSpine international study on 479

- patients. Spine. 2015 Sep 1;40(17):1322-8. PMID: 26020847
- 13. Behrbalk E, Salame K, Regev GJ, Keynan O, Boszczyk B, Lidar Z. Delayed diagnosis of cervical spondylotic myelopathy by primary care physicians. Neurosurg Focus. 2013 Jul;35(1):E1. PMID: 23815245
- 14. Mowforth OD, Davies BM, Kotter MR. "I am not delusional!" Sensory dysaesthesia secondary to degenerative cervical myelopathy. BMJ Case Rep. 2019 Apr;12(4):e229033. PMID: 30975783
- 15. 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]. Glob Spine J. 2022 Feb;12(1 Suppl):28S-38S. PMID: 35174734
- 16. Brannigan JFM, Davies BM, Stewart M, Smith S, Willison A, Ahmed S, et al. Degenerative cervical myelopathy education in UK medical schools: a national cross-sectional survey of medical students. Br J Neurosurg. 2022 Dec;36(6):728–36. PMID: 35950690
- 17. Eysenbach G. Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res. 2004 Sep 29;6(3):e132. PMID: 15471760
- 18. Tetreault L, Palubiski LM, Kryshtalskyj M, Idler RK, Martin AR, Ganau M, et al. Significant Predictors of Outcome Following Surgery for the Treatment of Degenerative Cervical Myelopathy: A Systematic Review of the Literature. Neurosurg Clin N Am. 2018 Jan 1;29(1):115-127.e35. PMID: 29173423
- 19. Hilton B, Tempest-Mitchell J, Davies B, Kotter M. Route to diagnosis of degenerative cervical myelopathy in a UK healthcare system: a retrospective cohort study. BMJ Open. 2019 May 1;9(5):e027000. PMID: 31061045
- 20. Waqar M, Wilcock J, Garner J, Davies B, Kotter M. Quantitative analysis of medical students' and physicians' knowledge of degenerative cervical myelopathy. BMJ Open. 2020 Jan;10(1):e028455. PMID: 31932384
- 21. Sam AH, Westacott R, Gurnell M, Wilson R, Meeran K, Brown C. Comparing single-best-answer and very-short-answer questions for the assessment of applied medical knowledge in 20 UK medical schools: Cross-sectional study. BMJ Open. 2019 Sep 1;9(9):e032550. PMID: 31558462
- 22. Tversky A, Kahneman D. Judgment under Uncertainty: Heuristics and Biases. 1974;185. PMID: 17835457
- 23. Pauker SG, Kassirer JP. The Threshold Approach to Clinical Decision Making. N Engl J Med. 1980 May 15;302(20):1109–17. PMID: 7366635
- 24. Pellinen J, French J, Knupp KG. Diagnostic Delay in Epilepsy: the Scope of the Problem. Curr Neurol Neurosci Rep. 2021 Nov 24;21(12):71. PMID: 34817723
- 25. Richards D, Morren JA, Pioro EP. Time to diagnosis and factors affecting diagnostic delay

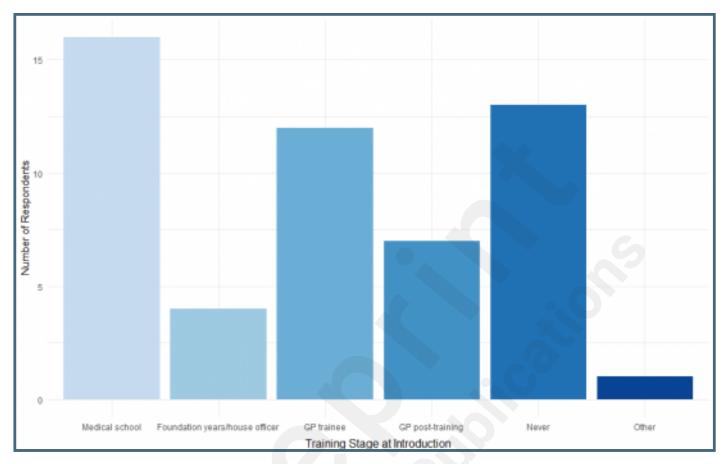
- in amyotrophic lateral sclerosis. J Neurol Sci. 2020 Oct 15;417:117054. PMID: 32763509
- 26. Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors. Alzheimer Dis Assoc Disord. 2009;23(4):306–14. PMID: 19568149
- 27. Falcão de Campos C, Gromicho M, Uysal H, Grosskreutz J, Kuzma-Kozakiewicz M, Oliveira Santos M, et al. Delayed Diagnosis and Diagnostic Pathway of ALS Patients in Portugal: Where Can We Improve? Front Neurol. 2021 Oct 27;12:761355. PMID: 34803894
- 28. Oto M (Meritxell). The misdiagnosis of epilepsy: Appraising risks and managing uncertainty. Seizure. 2017 Jan 1;44:143–6. PMID: 28017581
- 29. Jozefowicz RF. Neurophobia: The Fear of Neurology Among Medical Students. Arch Neurol. 1994 Apr 1;51(4):328–9. PMID: 25630779
- 30. Loftus AM, Wade C, McCarron MO. Primary care perceptions of neurology and neurology services. Postgrad Med J. 2016 Jun;92(1088):318–21. PMID: 26792634
- 31. McColgan P, McKeown PP, Selai C, Doherty-Allan R, McCarron MO. Educational interventions in neurology: a comprehensive systematic review. Eur J Neurol. 2013;20(7):1006–16. PMID: 24024931
- 32. The British Medical Association. An NHS under pressure [Internet]. 2023. https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/an-nhs-under-pressure [accessed 2024 Jan 5].
- 33. Biddle GJ, Thomas N, Edwardson CL, Clemes SA, Daley AJ. Burnout, psychological wellbeing, and musculoskeletal complaints in UK GPs: an observational study. BJGP Open. 2023 Dec;7(4):BJGPO.2023.0007. PMID: 37474254
- 34. 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 Mar;14(2):503–12. PMID: 35769029
- 35. Davies BM, Khan DZ, Mowforth OD, McNair AGK, Gronlund T, Kolias AG, et al. RE-CODE DCM (REsearch Objectives and Common Data Elements for Degenerative Cervical Myelopathy): A Consensus Process to Improve Research Efficiency in DCM, Through Establishment of a Standardized Dataset for Clinical Research and the Definition of the Research Priorities. Global Spine J. 2019 May;9(1 Suppl):65S-76S. PMID: 31157148
- 36. Hilton B, Tempest-Mitchell J, Davies B, Kotter M. Assessment of degenerative cervical myelopathy differs between specialists and may influence time to diagnosis and clinical outcomes. PLoS One. 2018 Dec 17;13(12):e0207709. PMID: 30557368
- 37. Nicholl DJ, Appleton JP. Clinical neurology: why this still matters in the 21st century. J Neurol Neurosurg Psychiatry. 2015 Feb;86(2):229–33. PMID: 24879832
- 38. Jiang Z, Davies B, Zipser C, Margetis K, Martin A, Matsoukas S, et al. The value of

- Clinical signs in the diagnosis of Degenerative Cervical Myelopathy A Systematic review and Meta-analysis. Global Spine J. 2023 Oct 30;21925682231209869. PMID: 37903098
- 39. Hilton B, Gardner EL, Jiang Z, Tetreault L, Wilson JRF, Zipser CM, et al. Establishing Diagnostic Criteria for Degenerative Cervical Myelopathy [AO Spine RECODE-DCM Research Priority Number 3]. Global Spine Journal. 2022 Feb 1;12(1\_suppl):55S-63S. PMID: 35174729
- 40. Pope DH, Mowforth OD, Davies BM, Kotter MRN. Diagnostic Delays Lead to Greater Disability in Degenerative Cervical Myelopathy and Represent a Health Inequality. Spine (Phila Pa 1976). 2020 Mar 15;45(6):368–77. PMID: 31658234
- 41. Goacher E, Phillips R, Mowforth OD, Yordanov S, Pereira EAC, Gardner A, et al. Hospitalisation for degenerative cervical myelopathy in England: insights from the National Health Service Hospital Episode Statistics 2012 to 2019. Acta Neurochir (Wien). 2022 Jun;164(6):1535–41. PMID: 35511406
- 42. Mowforth OD, Davies BM, Kotter MR. Quality of Life Among Informal Caregivers of Patients With Degenerative Cervical Myelopathy: Cross-Sectional Questionnaire Study. Interact J Med Res. 2019 Nov 7;8(4):e12381. PMID: 31697240

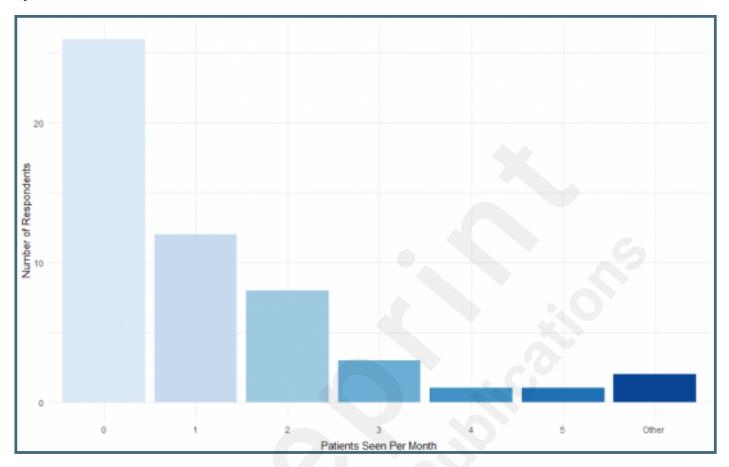
# **Supplementary Files**

# **Figures**

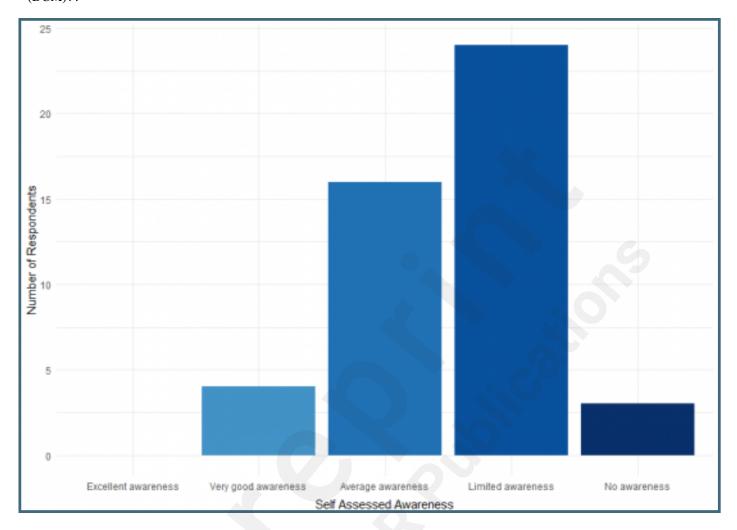
GP responses to the question 'At which stage of your training were you introduced to DCM, also historically known as cervical spondylitic myelopathy?'.



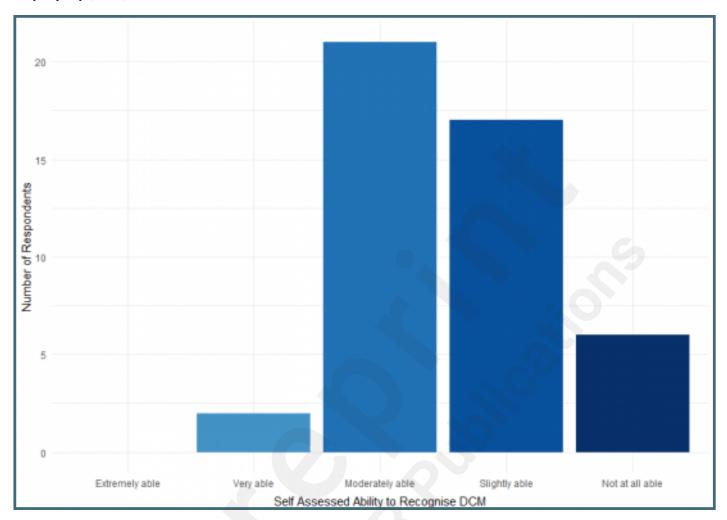
GP responses to the question 'Approximately how many patients with suspected DCM do you encounter, per month, in clinical practice?'.



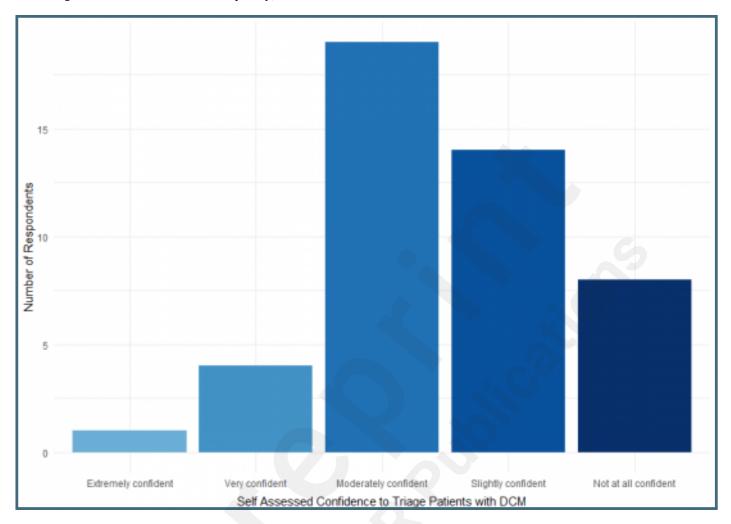
GP responses to the question 'How would you currently rate your awareness of myelopathy/degenerative cervical myelopathy (DCM)?'.



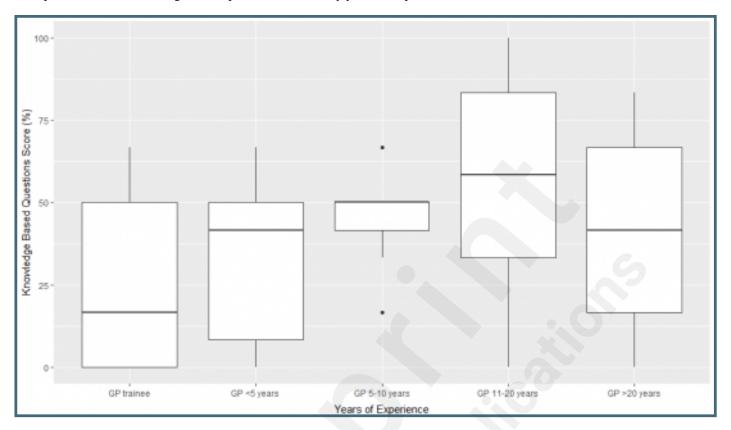
GP responses to the question 'How do you currently rate your ability to recognise myelopathy/degenerative cervical myelopathy (DCM)?'.



GP responses to the question 'If you suspect a case of DCM, how confident are you currently at triaging that patient (i.e., knowing where to refer them and how quickly)?'.



GP performance in knowledge-based questions stratified by years of experience.



# **Multimedia Appendixes**

Final survey design.

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Full data set.

URL: http://asset.jmir.pub/assets/d42aa37443672447852f826b0c8d163c.pdf