Year: 2023

Toward Shared Decision-Making in Degenerative Cervical Myelopathy: Protocol for a Mixed Methods Study

Sangeorzan, Irina ; Antonacci, Grazia ; Martin, Anne ; Grodzinski, Ben ; Zipser, Carl M ; Murphy, Rory K J ; Andriopoulou, Panoraia ; Cook, Chad E ; Anderson, David B ; Guest, James ; Furlan, Julio C ; Kotter, Mark R N ; Boerger, Timothy F ; Sadler, Iwan ; Roberts, Elizabeth A ; Wood, Helen ; Fraser, Christine ; Fehlings, Michael G ; Kumar, Vishal ; Jung, Josephine ; Milligan, James ; Nouri, Aria ; Martin, Allan R ; Blizzard, Tammy ; Vialle, Luiz Roberto ; Tetreault, Lindsay ; Kalsi-Ryan, Sukhvinder ; MacDowall, Anna ; Martin-Moore, Esther ; Burwood, Martin ; et al

Abstract: BACKGROUND Health care decisions are a critical determinant in the evolution of chronic illness. In shared decision-making (SDM), patients and clinicians work collaboratively to reach evidence-based health decisions that align with individual circumstances, values, and preferences. This personalized approach to clinical care likely has substantial benefits in the oversight of degenerative cervical myelopathy (DCM), a type of nontraumatic spinal cord injury. Its chronicity, heterogeneous clinical presentation, complex management, and variable disease course engenders an imperative for a patient-centric approach that accounts for each patient's unique needs and priorities. Inadequate patient knowledge about the condition and an incomplete understanding of the critical decision points that arise during the course of care currently hinder the fruitful participation of health care providers and patients in SDM. This study protocol presents the rationale for deploying SDM for DCM and delineates the groundwork required to achieve this. OBJECTIVE The study's primary outcome is the development of a comprehensive checklist to be implemented upon diagnosis that provides patients with essential information necessary to support their informed decision-making. This is known as a core information set (CIS). The secondary outcome is the creation of a detailed process map that provides a diagrammatic representation of the global care workflows and cognitive processes involved in DCM care. Characterizing the critical decision points along a patient's journey will allow for an effective exploration of SDM tools for routine clinical practice to enhance patient-centered care and improve clinical outcomes. METHODS Both CISs and process maps are coproduced iteratively through a collaborative process involving the input and consensus of key stakeholders. This will be facilitated by Myelopathy.org, a global DCM charity, through its Research Objectives and Common Data Elements for Degenerative Cervical Myelopathy community. To develop the CIS, a 3-round, web-based Delphi process will be used, starting with a baseline list of information items derived from a recent scoping review of educational materials in DCM, patient interviews, and a qualitative survey of professionals. A priori criteria for achieving consensus are specified. The process map will be developed iteratively using semistructured interviews with patients and professionals and validated by key stakeholders. RESULTS Recruitment for the Delphi consensus study began in April 2023. The pilot-testing of process map interview participants started simultaneously, with the formulation of an initial baseline map underway. CONCLUSIONS This protocol marks the first attempt to provide a starting point for investigating SDM in DCM. The primary work centers on developing an educational tool for use in diagnosis to enable enhanced onward decision-making. The wider objective is to aid stakeholders in developing SDM tools by identifying critical decision junctures in DCM care. Through these approaches, we aim to provide an exhaustive launchpad for formulating SDM tools in the wider DCM community. INTERNATIONAL REGISTERED REPORT IDENTIFIER (IRRID) DERR1-10.2196/46809.

Protocol

Toward Shared Decision-Making in Degenerative Cervical Myelopathy: Protocol for a Mixed Methods Study

Irina Sangeorzan[1], MSc; Grazia Antonacci[2,3], PhD; Anne Martin[4], BA; Ben Grodzinski[5], BA, MB, BChir; Carl M Zipser[6], MD; Rory K J Murphy[7], MD; Panoraia Andriopoulou[8], PhD; Chad E Cook[9,10,11,12], PT, PhD; David B Anderson[13], PT, PhD; James Guest[14], MD, PhD; Julio C Furlan[15,16], LLB, MBA, MSc, MD, PhD; Mark R N Kotter[1,17], MD, PhD; Timothy F Boerger[18], PhD, ATC; Iwan Sadler[1]; Elizabeth A Roberts[1], MA, MSc; Helen Wood[1], LLB, MA; Christine Fraser[19,20], MSc; Michael G Fehlings[21,22], MD, PhD; Vishal Kumar[23,24], MBBS, MS (Orth- PGI), DNB (MAMS), MNASc, Dip. SICOT; Josephine Jung[25,26], MD, PhD; James Milligan[27], MD, CCFP; Aria Nouri[28], MD, MSc; Allan R Martin[29], MD, PhD; Tammy Blizzard[1], DVM; Luiz Roberto Vialle[30], MD, PhD; Lindsay Tetreault[31], MD, PhD; Sukhvinder Kalsi-Ryan[16,32], BScPT, MSc, PhD; Anna MacDowall[33], MD, PhD; Esther Martin-Moore[1]; Martin Burwood[1]; Lianne Wood[34,35], BScPT, MSc, PhD; Abdul Lalkhen[36], MB ChB, MSc; Manabu Ito[37], MD, PhD; Nicky Wilson[38], MSc, PhD; Caroline Treanor[39,40,41], BSc, MSc, PT; Sheila Dugan[1]; Benjamin M Davies[1,17], MBChB(Hons), MPhil, MRCS

[1]Myelopathy.org, Cambridge, United Kingdom

[2]Department of Primary Care and Public Health, National Institute of Health Research (NIHR) Applied Research Collaboration (ARC) Northwest London, Imperial College London, London, United Kingdom

[3]Centre for Health Economics and Policy Innovation (CHEPI), Business School, Imperial College London, London, United Kingdom

[4]Faculty of Medicine, Health and Social Care, Canterbury Christ Church University, Canterbury, United Kingdom

[5]University Hospitals Sussex, NHS Foundation Trust, Brighton, United Kingdom

[6]Spinal Cord Injury Center, Balgrist University Hospital, Zurich, Switzerland

[7]Department of Neurosurgery, Barrow Neurological Institute, St. Joseph's Hospital and Medical Center, Phoenix, AZ, United States

[8]Psychology Department, School of Social Sciences, University of Ioannina, Ioannina, Greece

[9]Division of Physical Therapy, School of Medicine, Duke University, Durham, CA, United States

[10]Department of Orthopaedics, School of Medicine, Duke University, Durham, CA, United States

[11]Department of Population Health Sciences, School of Medicine, Duke University, Durham, CA, United States

[12]Duke Clinical Research Institute, Duke University, Durham, CA, United States

[13]Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

[14]The Miami Project to Cure Paralysis, The Miller School of Medicine, University of Miami, Miami, FL, United States

[15]Division of Physical Medicine and Rehabilitation, Department of Medicine, University of Toronto, Toronto, ON, Canada

[16]The KITE Research Institute, Toronto Rehabilitation Institute, University Health Network, Toronto, ON, Canada

[17]Department of Clinical Neurosurgery, University of Cambridge, Cambridge, United Kingdom

[18]Department of Neurosurgery, Medical College of Wisconsin, Milwaukee, WI, United States

[19]Department of Health Sciences, University of Stirling, Scotland, United Kingdom

[20]Physiotherapy Department, National Health Service Lothian, Edinburgh, United Kingdom

[21]Division of Neurosurgery and Spine Program, Department of Surgery, University of Toronto, Toronto, ON, Canada

[22]Division of Neurosurgery, Krembil Neuroscience Centre, Toronto Western Hospital, University Health Network, Toronto, ON, Canada

[23]Department of Orthopaedics, Postgraduate Institute of Medical Education and Research, Chandigarh, India

[24]Department of Orthopaedics, All India Institute of Medical Sciences, Deoghar, India

[25]Institute of Psychiatry, Psychology & Neuroscience, King's College, London, United Kingdom

[26]Department of Neurosurgery, King's College Hospital, London, United Kingdom

[27]Department of Family Medicine, McMaster University, Hamilton, ON, Canada

[28]Division of Neurosurgery, Geneva University Hospitals, University of Geneva, Geneva, Switzerland

[29]Department of Neurological Surgery, University of California, Davis, Davis, CA, United States

[30]School of Medicine, Pontifical Catholic University of Paraná, Curitiba, Brazil

[31]Department of Neurology, New York University, New York, NY, United States

[32]Department of Surgery, University of Toronto, Toronto, ON, Canada

[33]Department of Surgical Sciences, Uppsala University and Department of Orthopaedics, The Academic Hospital of Uppsala, Uppsala, Sweden

[34]Faculty of Health and Life Sciences, University of Exeter, Exeter, United Kingdom

[35]NeuroSpinal Assessment Unit, Nottingham University Hospitals NHS Trust, Nottingham, United Kingdom

[36]Northern Care Alliance, Salford Royal NHS Foundation Trust, Manchester, United Kingdom

[37]Department of Orthopaedic Surgery, National Hospital Organization Hokkaido Medical Center, Sapporo, Japan

[38]Physiotherapy Department, King's College Hospital NHS Foundation Trust, London, United Kingdom

[39]Department of Physiotherapy, Beaumont Hospital, Dublin, Ireland

[40]Department of Neurosurgery, Beaumont Hospital, Dublin, Ireland

[41]School of Physiotherapy, Royal College of Surgeons in Ireland, Dublin, Ireland

Corresponding Author:
Benjamin M Davies, MBChB(Hons), MPhil, MRCS
Department of Clinical Neurosurgery
University of Cambridge
Box 167, Cambridge Biomedical Campus
Addenbrooke's Hospital
Cambridge, CB2 0QQ
United Kingdom
Phone: 44 7766 692608
Email: bd375@cam.ac.uk

Abstract

Background: Health care decisions are a critical determinant in the evolution of chronic illness. In shared decision-making (SDM), patients and clinicians work collaboratively to reach evidence-based health decisions that align with individual circumstances, values, and preferences. This personalized approach to clinical care likely has substantial benefits in the oversight of degenerative cervical myelopathy (DCM), a type of nontraumatic spinal cord injury. Its chronicity, heterogeneous clinical presentation, complex management, and variable disease course engenders an imperative for a patient-centric approach that accounts for each patient's unique needs and priorities. Inadequate patient knowledge about the condition and an incomplete understanding of the critical decision points that arise during the course of care currently hinder the fruitful participation of health care providers and patients in SDM. This study protocol presents the rationale for deploying SDM for DCM and delineates the groundwork required to achieve this.

Objective: The study's primary outcome is the development of a comprehensive checklist to be implemented upon diagnosis that provides patients with essential information necessary to support their informed decision-making. This is known as a core information set (CIS). The secondary outcome is the creation of a detailed process map that provides a diagrammatic representation of the global care workflows and cognitive processes involved in DCM care. Characterizing the critical decision points along a patient's journey will allow for an effective exploration of SDM tools for routine clinical practice to enhance patient-centered care and improve clinical outcomes.

Methods: Both CISs and process maps are coproduced iteratively through a collaborative process involving the input and consensus of key stakeholders. This will be facilitated by Myelopathy.org, a global DCM charity, through its Research Objectives and Common Data Elements for Degenerative Cervical Myelopathy community. To develop the CIS, a 3-round, web-based Delphi process will be used, starting with a baseline list of information items derived from a recent scoping review of educational materials in DCM, patient interviews, and a qualitative survey of professionals. A priori criteria for achieving consensus are specified. The process map will be developed iteratively using semistructured interviews with patients and professionals and validated by key stakeholders.

Results: Recruitment for the Delphi consensus study began in April 2023. The pilot-testing of process map interview participants started simultaneously, with the formulation of an initial baseline map underway.

Conclusions: This protocol marks the first attempt to provide a starting point for investigating SDM in DCM. The primary work centers on developing an educational tool for use in diagnosis to enable enhanced onward decision-making. The wider objective is to aid stakeholders in developing SDM tools by identifying critical decision junctures in DCM care. Through these approaches, we aim to provide an exhaustive launchpad for formulating SDM tools in the wider DCM community.

International Registered Report Identifier (IRRID):   DERR1-10.2196/46809

(JMIR Res Protoc 2023;12:e46809)   doi: 10.2196/46809

XSL·FO

RenderX

KEYWORDS

degenerative cervical myelopathy; spine; spinal cord; chronic; aging; geriatric; patient engagement; shared decision-making; process mapping; core information set; decision-making; patient education; common data element; Research Objectives and Common Data Elements for Degenerative Cervical Myelopathy; RECODE-DCM

Introduction

Background

Degenerative cervical myelopathy (DCM) [1,2] arises when age-related changes progressively narrow the cervical spinal cord canal, resulting in neurological dysfunction secondary to cord compression [3]. Its exact epidemiology is poorly understood, likely owing to widespread underdiagnosis [4,5]. However, estimates based on imaging studies suggest that DCM could affect as many as 1 in 50 adults [2]. Although surgical decompression can halt disease progression and afford varying levels of recovery in functional status, pain, and quality of life [6-8], most people with DCM [9] will experience lifelong residual disability despite treatment [8,10]. This is often associated with a poor quality of life [11,12], high unemployment rates [8,13], and mental health difficulties [10]. From a socioeconomic point of view, DCM places a substantial financial burden on society [14,15]. In England, United Kingdom, alone, the cumulative costs associated with disability payments, lost productivity, and hospital admission are conservatively estimated at £0.7 billion (US $0.9 billion) per annum [15]. Moreover, DCM affects not only people with DCM but also their families and caregivers, who experience a low quality of life owing to caregiving strain [16]. As the incidence of DCM is expected to increase with aging populations [17], interventions that target the human and economic cost of illness associated with this condition represent an immediate priority for global health care systems and the wider community [18]. Shared decision-making (SDM) represents one such potential cost containment and patient outcome improvement strategy that could be implemented.

A Role for SDM in DCM

Involving patients in collaborative deliberations about their care can foster improved clinical outcomes [19,20] and curtail the needless use of health care resources [21,22]. The epitome of this patient-centric paradigm is SDM, an approach to clinical care wherein clinicians and patients work together to reach evidence-based solutions that prioritize patients' values and preferences [23,24].

Over several decades of scholarship since its emergence in the early 1980s [25], SDM has risen to prominence as a hallmark of quality clinical practice, notably in the realm of unresolved, chronic illnesses [26]. Given the evolving and cyclic nature of many chronic conditions, continual reevaluation and adjustment of initial health management judgments are often required as patients progress through the trajectory of their illness [27-29]. Furthermore, the complexity of chronic illnesses tends to expand over time, presenting patients and health care providers with multiple options, each with its own set of benefits and drawbacks [30]. By engaging patients in the decision-making process and considering the unique circumstances and preferences of each patient along with the potential trade-offs of each option [31],

SDM can facilitate the selection of the most appropriate course of action, ultimately leading to improved health outcomes [32]. Indeed, the health management decisions of people with chronic illnesses are optimal when founded on consideration of their preferences, values, and circumstances [33-36].

Therefore, the application of SDM in DCM is likely highly pertinent. People with DCM encounter care decisions that are contingent upon personal, contextual, and technical factors on a fairly recurrent basis [13,37,38]. For example, the clinical manifestation of DCM has a diverse spectrum, with symptomatology that varies from person to person [39]. In the views of people with DCM, seemingly unrelated ailments such as loss of bowel or bladder control can be traced back to the spinal cord [2]. This is important as efficient monitoring of neurological deterioration and understanding when to report novel or developing symptoms is critical [40]. The decision to undergo surgery is a significant consideration, as evidenced by the frequent queries of people with DCM about the suitability of surgery and the best type of surgery for their circumstances [13,37]. For those treated surgically, a range of surgical approaches can address the degenerative changes in the cervical spine [41]. Nonetheless, the decision to offer surgery and its timing is nuanced owing to its risks and the potential for DCM to remain mild [42]. Furthermore, surgery seldom leads to a full recovery; instead, a heterogeneous and lifelong disability is generally expected [8,10-13]. The implications of this can involve multiple distinct complex care pathways, necessitating collaboration across an array of health care disciplines less familiar with DCM [43]. Therefore, it is essential that people with DCM are well prepared to navigate a host of complex decisions. Finally, although treatment decisions are often the focus of SDM tools [44], they represent one of many care decisions that patients encounter [45]. Our experience at Myelopathy.org, a DCM scientific and clinical charity, is that patient health care inquiries encompass a broad spectrum, ranging from "should I modify my day-to-day activities?" to "should I undergo a dynamic MRI?" This variability underscores the diverse range of decisions that people with DCM confront, necessitating decisional support. It is also our experience that these inquiries are often hindered by patients' inadequate knowledge and perhaps misconceptions of DCM [45]. In this regard, people with DCM are poorly supported by a lack of comprehensive, patient-centric, and up-to-date educational resources [45].

The aforementioned considerations, coupled with the inherent recurrent nature of decision-making in DCM, underscore the pressing need for people with DCM to engage in meaningful dialogue with health care professionals (HCPs) and have access to high-quality decisional support. In line with other chronic illness research, we hypothesize that a structured and well-orchestrated communication framework, as formulated within SDM tools, is ideally placed to successfully guide people with DCM through their health journey. Thus, investigating this

area is warranted. In addition, the strategic incorporation of SDM has the potential to aptly support knowledge translation endeavors by identifying critical knowledge gaps and providing a framework for the assimilation of new knowledge into clinical practice [45-47]. This is currently a major challenge in DCM, where awareness of the condition continues to be suboptimal in the medical profession [48]. This is even conspicuous among spinal surgeons, who are considered authorities in the field of DCM [49,50]. To illustrate, a retrospective analysis of surgical decision-making in the United Kingdom found that only the amount of cord compression (as opposed to the guideline recommendations of disease severity) predicted the likelihood of a patient being offered surgery [49,51-53]. As the patient is perhaps the most motivated stakeholder and, importantly, a more recent student of DCM, addressing SDM may also support more consistent and immediate evidence-based care [54-57].

The Rationale for Developing a Core Information Set and Process Mapping Patients' Health Care Journeys

Patients' understanding of their baseline circumstances represents a fundamental starting point for SDM [58]. This is crucial for patients to aptly recognize care options and articulate their preferences [59]. Core information sets (CISs) were pioneered as a means to support informed consent before surgery [60-62] and comprise a distilled list of information items akin to a checklist. Their purpose is to guide an educational conversation between HCPs and their patients by ensuring that critical information about a topic is shared and considered. CISs can help reduce variation in the practice of providing information to patients [63]. Their structured and condensed nature can also circumvent the potential for information overload [64]. Therefore, a DCM CIS centered on delivering information material to the diagnosis stage could assist the efficiency of clinical interactions and quality of onward health decisions by improving patients' knowledge of the condition and their circumstances. As CISs are coproduced using multistakeholder input, their consensus-derived nature would also ensure that the information considered is of agreed importance to both professionals and patients.

Beyond diagnosis, the successful development of SDM tools depends on characterizing the critical decision points along patients' care pathways [65]. A key aspect of quality improvement interventions is identifying whether and when a decision is required [66,67]. Process mapping, the diagrammatic representation of workflows, is frequently used in health settings to understand care processes [68]. By capturing all relevant steps in a sequence of actions, a process map can provide a comprehensive overview of an activity and its potential strengths, vulnerabilities, and limitations. As with CISs, process maps are coproduced via the input of key stakeholders who describe the workflows and cognitive decisions associated with a process [69,70]. Therefore, process mapping the key decisions of people with DCM is instrumental in paving the way for the development of SDM tools, ensuring their foundation in clearly delineated needs.

This research protocol describes the preliminary groundwork required to enable the exploration of SDM tools for DCM. First, we outline the development of a DCM CIS tailored to guide a material discussion between professionals and their patients at diagnosis. Second, we detail the procedure for formulating a global DCM process map that comprehensively captures common critical decisions in the patient journey.

Methods

Overview and Scope

Myelopathy.org and the Research Objectives and Common Data Elements for Degenerative Cervical Myelopathy Community

Myelopathy.org is the first and currently only scientific and clinical charity dedicated to improving the outcomes of people with DCM [71]. The charity has a global professional and lay audience, making it well suited for spearheading the initiative described in this protocol, which forms part of a larger enterprise aimed at promoting SDM in DCM. This will occur through the Research Objectives and Common Data Elements for Degenerative Cervical Myelopathy (RECODE-DCM) platform, an international community of professionals with diverse expertise in spinal care, and people with DCM registered with the charity working together to accelerate knowledge discovery in DCM.

The community was formed in collaboration with AO Spine (a nonprofit organization supporting education and research for spinal surgeons) to develop a research toolkit aimed at accelerating knowledge discovery in DCM [1,4,18,72]. Recognizing the broader opportunities for this community to address knowledge gaps in DCM and support their implementation led to its recognition as a distinct entity [73-75]. The network is now maintained by Myelopathy.org under its advisory board.

The research team formulated 2 objectives for this study, as outlined in the following sections.

Objective 1: To Enhance Knowledge of the Condition Among People With DCM

This will be achieved by developing the first DCM diagnosis CIS using an international multistakeholder (Delphi) consensus process.

Objective 2: To Identify Critical Decision Points in the Medical Care Product Life Cycle That May Benefit From SDM Tools

This will be achieved through a process map exercise involving an international multidisciplinary team of key stakeholders, including patient representatives.

Information on the status of each phase is shown in Table 1.

Table 1. Research study stages, findings summary, and status.

Description	Findings summary	Status
Core information set		
Scoping literature review of educational resources in DCM[a]	>80% of resources geared toward professionals	Completed
Semistructured patient interviews	Varied information needs throughout the patient journey	Completed
Survey of professionals	Survey of professionals to collect their views on the information that people with DCM need	Completed
Delphi consensus survey of professionals and patients	Pending	In preparation
Process mapping		
Preparation, planning, and process identification	Pending	Completed
Data gathering	Pending	In planning
Process map generation	Pending	In planning
Analysis	Pending	In planning
Taking it forward	Pending	In planning

[a]DCM: degenerative cervical myelopathy.

Study Design

Enacting SDM requires insight into decisional dynamics. At its core, this entails discerning the critical timing of decisions and navigating factors related to decisional conflict—a state of uncertainty over a course of action when multiple options are present, each requiring careful evaluation of risks, benefits, and alignment with personal values. Key among the latter is an understanding of the informational demands associated with each decision-making juncture. To meet these requirements, our protocol proposes a mixed methods design that combines the structured, quantitative Delphi consensus procedure with the qualitative, visual approach of process mapping. By leveraging both methods, our study aims to translate evidence-based knowledge and stakeholder experiences into clinically actionable tools for enhancing the health outcomes of people with DCM [76]. The following sections elaborate on our application of the Delphi procedure in constructing the first DCM CIS and process mapping to highlight patients' key decision points.

Objective 1: To Enhance People With DCM's Knowledge of the Condition—Developing the First CIS for Use in DCM at Diagnosis

Delphi Consensus Process Overview

The Delphi technique is a well-established method for achieving consensus among experts on a given topic [77]. It is particularly suited to contexts in which knowledge is ambiguous, empirical evidence is scarce, or priority setting is required [78]. In this procedure, a panel of preselected experts are engaged in a series of structured surveys. Each round incorporates controlled feedback, usually a blend of quantitative and qualitative data, the purpose of which is to foster insights from previous rounds, prompting reflection and the potential revision of viewpoints [79]. Designed to incrementally foster a convergence of opinions, the procedure is usually conducted anonymously, allowing participants to freely articulate their perspectives [80]. The number of rounds, execution of question delivery and response acquisition, and standards of achieving of "consensus" can vary within this general framework. Figure 1 provides a schematic overview of our approach, comprising 2 anonymized web-based surveys followed by a consensus meeting hosted over the internet. Consensus meetings offer a platform for real-time dialogue [81]. This face-to-face component has been observed to play a role in refining and enhancing the group's collective understanding, paving the way for a more sophisticated consensus [82].

The Delphi method has been widely used in health sciences [83] to generate clinical recommendations [84] and standards and guidelines for theoretical or methodological issues [83,85,86] for a range of chronic illnesses such as diabetes [87,88], cancer [89,90], asthma [91], rheumatoid arthritis [92], and spinal cord injury [93,94]. Our objective using a Delphi procedure is to develop a CIS that facilitates optimal communication of information to people with DCM about the condition at the point of diagnosis. Figure 2 shows an overview of the phases involved in developing the CIS.

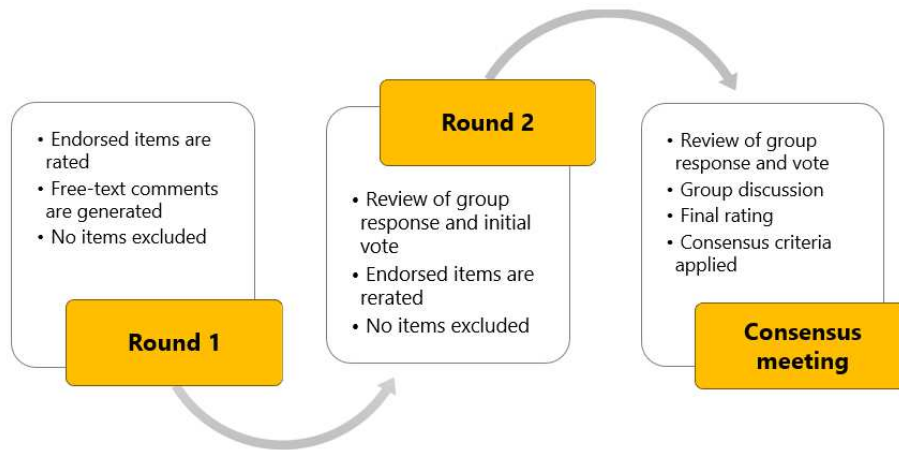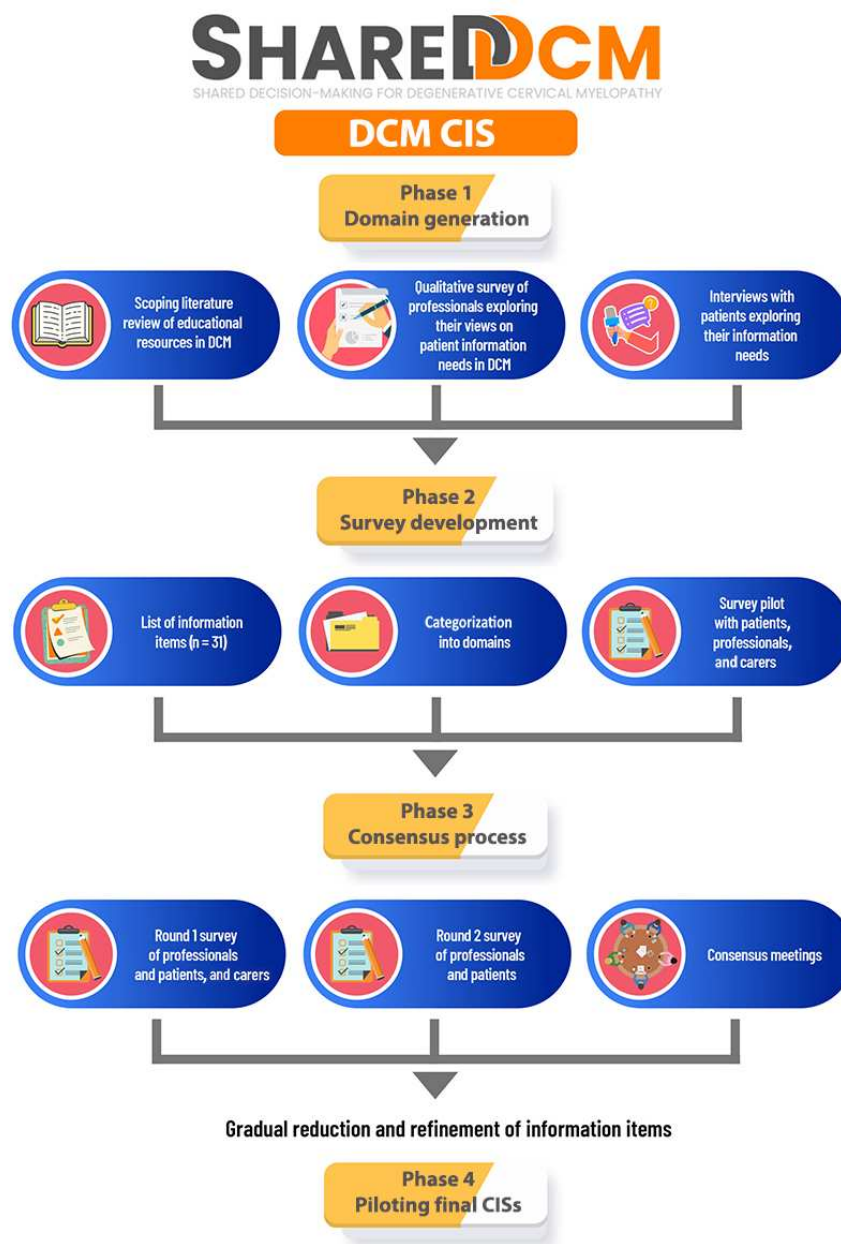**Figure 1.** Overview of the Delphi rounds and consensus meeting.

Figure 2. Overview of the phases involved in the development of the degenerative cervical myelopathy (DCM) diagnosis core information set (CIS).

Sample Size

The optimal participant head count for a Delphi study remains a subject of ongoing discussion [82], as exemplified by the historical variance in sample sizes [95]. However, representativeness is not shaped by conventional sampling strategies [96,97] but rather through the expertise of the panel members [98]. Guidelines suggest a minimum of 7 to 15 panelists for optimal reliability [78]. Some believe that exceeding 30 participants adds little value [99-101]. To develop a relevant CIS, our study aims to target the 2 primary DCM stakeholders: people with DCM and HCPs managing DCM. We propose enlisting at least 15 experts from each category, with no upper limit [78,95,102]. We address potential carer involvement in the following section.

Expert Selection

The sample composition significantly determines the validity of the study results [103,104]; therefore, an element of careful judgment is warranted to ensure a "balanced" panel [104-106]. To ensure a judicious selection of experts, this study will use a purposive sampling approach, drawing surgeons, other HCPs, and people with DCM as participants from the specialized RECODE-DCM community. People with DCM will be considered if they (1) have been formally diagnosed with DCM and are at least 6 months after surgical decompressive treatment, the time point at which neurological recovery is considered to halt for most [107], or (2) have undergone at least 6 months of nonoperative management [49]. Professional stakeholders will be invited to participate if they (1) are experienced in managing DCM for at least 5 years; (2) belong to key clinical disciplines, including spinal surgery, neurology, combined physical and psychological rehabilitation medicine, physiotherapy, pain management, and primary care [4,108]; and (3) have no conflict of interest in developing a CIS. All participants will be English-speaking adults (aged ≥18 years).

A diverse and geographically representative panel will be sought, in keeping with the aim of developing an internationally suitable CIS. Adequate patient involvement is vital to this endeavor to help foster evidence-based decision-making [109]. Recognizing the importance of patient perspectives, we propose aiming for a stakeholder target ratio of 1:1:2 (surgeons:other HCPs:people with DCM). The increased representation of people with DCM addresses their typically minor role in such studies and considers recent findings indicating a divergence in clinician- and patient-prioritized outcomes [4] and information needs [45]. This ratio also aligns with the status of people with DCM as the principal beneficiaries of the CIS and enhances its applicability from a patient and public perspective.

For balanced geographical stakeholder representation, a 1:1:1 target ratio is proposed, spanning North America and Australasia; Europe and the United Kingdom; and "elsewhere," comprising Africa and Asia. Including stakeholders from these regions will help ensure that the CIS considers a wide range of health care systems, cultural practices, and resource availability. However, it is worth noting that engaging participants from the "elsewhere" category may prove difficult. These regions, which are often underrepresented in the research community owing to fewer research resources and infrastructure [110], are

similarly underrepresented in our specialized RECODE-DCM community. Recognizing this potential recruitment challenge upfront, we will aim to achieve equal regional representation during the final consensus meeting, with no items removed before this stage.

Carers (informal and formal) of people with DCM will also be invited to participate in the Delphi process as they offer significant practical and emotional support to people with DCM [16] and likely hold unique perspectives with regard to their information needs at the time of diagnosis. Consultation with informal carers, often subject to significant caregiving strain [16], may indirectly contribute to their welfare by promoting improved standards of care. However, we acknowledge that the recruitment of carers may be challenging as they are less likely to self-identify, as documented in related research domains [111]. In addition, the number of carers involved in the RECODE-DCM community is currently limited. For these reasons, no stakeholder or geographical target ratios will be specified for this group. Their involvement will be encouraged by existing HCPs and people with DCM in the community.

Participants will be invited to complete round 2 of the Delphi survey only if they have responded to round 1. A dropout rate of approximately 20% is expected from previous Delphi exercises [95,112]. Respondents who complete the Delphi process will be acknowledged in published material. No monetary incentives will be offered.

Generating Information Items

The first step in the Delphi process involves generating a list of information items for the voting consensus process. The procedure comprises 3 steps, described in the following sections.

Scoping Literature Review and Patient Interviews

In structuring the Delphi procedure, we sought to cover the wide spectrum of DCM-related information with the potential to foster patient understanding of the condition, facilitate informed decision-making, and promote efficient self-management. Clinically pertinent items were derived from scientific publications, patient leaflets, health websites, and videos identified in a scoping review of DCM education resources [38]. In total, 150 information resources were reviewed, spanning 115 (76.7%) scientific publications, 28 (18.7%) videos, and 7 (4.7%) health organization resources and health education websites. Items sourced in this manner characterized the disease etiology, pathophysiology, epidemiology, management, and outcome prediction. Additional multidimensionality was added via items sourced from qualitative research involving patient focus groups [10,113] and semistructured interviews [45]. These provided valuable additions focused on the impact of DCM on employment, mental health, and quality of life. The process of deriving the information items was iterative. Each new unique piece of information was noted as an item, and multiple returns to the data were made to ensure the avoidance of duplicates and omissions. This process continued until a preliminary list of information items (n=95) was collated and no new items could be identified.

Professionals' Perspectives

Professionals' views on the information items to be included in the diagnosis CIS were identified using an open-ended qualitative questionnaire (SurveyMonkey; Momentive Inc). Respondents were provided with relevant information via a web hyperlink to the Participant Information Sheet. The sheet included a summary of the research project, its objectives, the inclusion and exclusion criteria, anonymity and confidentiality, and the anticipated time commitment required to complete the survey. To stimulate participant engagement, a short educational video explaining the purpose of the procedure was presented [114]. Biographical information, including training specialty (surgery or other HCP), was collected from consenting participants. Respondents were subsequently directed to a page containing the following open-ended question: "What information do you think people with DCM need to be told at the point of diagnosis about their condition?" It is acknowledged that free-text questions do not generate rich qualitative data [115]. However, our objective was not to elicit robust qualitative insights but rather to generate a list of information items from the professionals' perspectives. To mitigate this limitation, participants were asked to provide a short rationale for each recommended information item. This approach can act as a proxy for qualitative interviews administered to convenience samples [116] and allowed the study team to improve evaluative rigor by understanding the rationale behind the recommendations received. There was no limit on the number of information items that the HCPs could submit.

To facilitate reflective consideration from respondents, participants were presented with a word cloud upon submitting their initial recommendations (Multimedia Appendix 1). Word clouds are a graphic representation of textual data that use frequency counts to display effective summaries of common themes within a given text [117] and have been successfully used previously in DCM consensus work [118,119]. The word cloud generated for this study was produced using qualitative codes derived from the thematic analysis of interviews with people with DCM on the topic of their information needs [45]. This approach was selected to mitigate issues related to language variability that can arise from using direct quotes from the participants, which may be influenced by individual differences in language proficiency, education, and cultural background, and to improve the comprehensibility of the word cloud. Similar adjusted approaches have been used by others [117]. Participants were asked to reconsider their recommendations after viewing the word cloud. As word clouds have been found to promote critical thinking and reflection [120], we hypothesized that this approach would help stimulate professional stakeholders to generate insightful recommendations that are better aligned with patients' needs. The open-ended questionnaire was not issued to people with DCM as their perspectives have already been collected [45].

The Questionnaire

A total of 46 respondents, predominantly spinal surgeons (n=33, 72%), suggested information items (n=312) for inclusion in the Delphi survey. Contributors also included physiotherapists (8/46, 17%) and other HCPs, including neurologists, family physicians, allied health professionals, and researchers (5/46,

11%). The items received were carefully scrutinized for redundancy. On inspection, suggestions paralleled our existing list, demonstrating a broad alignment across all information sources, including the expert clinician group. A multidisciplinary study committee comprising 3 people with DCM, 3 neurosurgeons, a neurologist, 2 consultant physiotherapists, a lay representative, and the study coresearcher condensed the list to 31 information items and classified them into 8 distinct categories deemed to accurately represent their content. For the purposes of developing a CIS, the term "information item" was conceptualized as overarching categories or topics that house more specific, detailed information. For example, the item "lifestyle factors" was an inclusive banner for detailed subjects such as the effects of smoking and occupational trauma on DCM. This approach was chosen to ensure the appraisal of *meaningful* concepts or core educational aspects. The detailed content within each item, although not voted upon, will be accessible for participants' reference throughout the Delphi study. Categorizing information items in Delphi studies is crucial in reducing redundancy and ensuring that all relevant concepts are captured as well as promoting consensus building among expert panelists by clarifying the meaning of each item [79,80]. This also facilitates a systematic and standardized approach to synthesizing diverse perspectives, thereby generating informed recommendations [79,121]. In preparation for pilot-testing, the research team created a draft survey based on the final list and evaluated the software settings, automation, flow, ease of navigation, and completion time. For ease of navigation, only 1 information item was presented per page [122].

Pilot Survey

Pilot-testing was conducted with the study committee. Feedback concerning the language, structure, readability, comprehension of statements, and formatting of the questionnaire was collected through open- and closed-ended questions.

Delphi Survey

An email campaign will be created in Gmail (Google) using a newsletter layout template and sent to HCPs, people with DCM, and carers in the contact directory of the RECODE-DCM network using the multisend function. The multisend option is a built-in mass-email feature that allows emails to be sent in bulk to distinct recipients, thus preserving their anonymity, which is a key feature of the Delphi method [98]. Participants will have the option to opt out of the process at any point through a unique "unsubscribe" link automatically added to each email. Recipients who unsubscribe will be removed from future email campaigns. The email will provide prospective Delphi panelists with a brief overview of the study. Potential panelists will be directed to Delphi round 1 via a SurveyMonkey web link embedded in a participation button at the bottom of the email. The survey will open to a short explanatory video and a web link to the Participant Information Sheet, which will provide a summary of the research project, aims, the inclusion and exclusion criteria, anonymity and confidentiality, and anticipated time commitment. The following biographical data will be collected for people with DCM: age, year of diagnosis, history of surgery or nonoperative management, and employment status. For HCPs, information about their

profession, specialty, job title, and experience in managing DCM will be captured.

Panelists will be asked to independently rate the importance of information items using a 4-point Likert scale ("essential," "very important," "unimportant," and "not at all important"). This range of response categories is more likely to produce stable findings in Delphi studies [95]. Respondents will also be asked to provide a brief rationale for their responses and whether the information items presented could be modified to improve their relevance using a comment box. It is common practice to include in questionnaires that respondents themselves complete an invitation to add issues not covered in the main part of the questionnaire or to expand on terms [123]. The presentation of information items will be randomized using a pseudorandom number generator throughout both rounds [124]. No more than 3 rounds will take place to ensure that the process does not become too repetitive and time-consuming to maintain an adequate response rate [80]. After each round, participants will be asked to read the feedback before responding again to statements.

Data Analysis

Overview

Qualitative and quantitative summaries will be used to understand areas of agreement or disagreement between panelists, generate feedback, and stimulate participants' reflections. All forthcoming data analyses will be carried out by a postgraduate research assistant. Both quantitative and qualitative methods will be used to analyze interround feedback, and the findings will be reported to the panelists and the core research team after each round. The provision of both types of data is essential to enhance rating accuracy [125].

Qualitative Analysis

Free-text comments will be analyzed using inductive content analysis [126], a procedure commonly used with text-based

data. Its pragmatic emphasis on theoretical constructs makes this approach particularly suited to practically oriented research where the goal is to describe a phenomenon of interest [127] and generate answers for the application of findings [128]. A summary of the remarks made by other panelists will be displayed anonymously to participants after each round.

Descriptive Statistics

Following each round, panelists will receive aggregate-level summary statistics for each item in the form of frequency percentages, medians, ranges, and IQRs [129]. Participation and attrition rates will be summarized as frequencies and percentages after round 2. Participants will be asked to read the summarized feedback before responding to round 2 statements.

Interrater Stability

Descriptive statistics reflect the level of overall consensus in a given sample but may not account for random change agreement and, therefore, may fail to accurately depict "true" consensus [130]. The κ statistic measures agreement beyond that expected by chance [130]. A weighted κ coefficient will be calculated after round 2 for the between-participant agreement on each information item. This variant is preferred compared with its unweighted equivalent as it is more suited to ordinal data given its ability to account for the magnitude of differences between the agreement levels [131]. The κ statistic will be particularly helpful for guiding the direction of conversations during the consensus meeting, ensuring that discussions are rooted in objective findings. κ calculations will be provided for each information item along with the reference value description of the agreement level in accordance with the study by McHugh [132] (Table 2).

No information items will be removed during these rounds. Data analyses will be conducted using SPSS (version 26; IBM Corp), and graphs will be produced using Microsoft Excel (Microsoft Corp).

Table 2. Level of agreement represented by κ values[a].

κ value	Agreement level
0.0-0.2	None
0.21-0.39	Minimal
0.40-0.59	Weak
0.60-0.79	Moderate
0.80-0.90	Strong
≥0.90	Almost perfect

[a]Adapted from the study by McHugh [132].

Consensus Criteria

Delphi studies lack consensus on the specific threshold for agreement. Significantly, Linstone and Turoff [133] posit that an agreement of >80% is neither the central objective of the Delphi process nor always practically possible. In this study, items rated as "essential" or "very important" by ≥75% will qualify for inclusion, whereas those judged as "unimportant"

or "not at all important" by ≥75% will qualify for exclusion. Items not fulfilling these criteria will be defined as not having reached a consensus. This threshold value [134,135] is situated between the 50% consensus supported by some [136,137] and the 100% cutoff point suggested by others [138]. Consensus criteria will be applied after the consensus meeting.

To gain additional insights into the perspectives of the 3 stakeholder groups, comparative statistics will be calculated

after each round for review by the core study team. The parametric 1-way ANOVA will be used to investigate differences in stakeholder responses during each round if the assumptions of normal distribution and homoscedasticity are met [139]. These will be inspected using histograms and the Shapiro-Wilk test and the Levene test for equality of variances, respectively. Statistically significant results will be investigated using post hoc analyses to be chosen in accordance with whether homoscedasticity is met [140]. In the event of violations of the assumptions of normality, the Kruskal-Wallis *H* test, a nonparametric alternative, will be used as it is predicated on rank-based assessment and does not presuppose normality or homogeneity of variance [141]. Moreover, in the event that we are unable to identify sufficient carers to complete the Delphi survey, we will use the independent-sample 2-tailed *t* test to investigate statistically significant differences between HCPs and people with DCM. If the assumptions for the test are not met, we will use its nonparametric equivalent, the Mann-Whitney *U* test. Significance will be assumed at $P < .05$.

Consensus Meeting

The consensus meeting via Google Meet (Google LLC) will be attended by a maximum of 20 randomly selected HCPs, people with DCM, and carers who have completed both rounds of the Delphi survey, preserving the key stakeholder and geographical representation previously described. Participants will be presented with round 2 voting results, as previously described, and asked to anonymously rate the importance of each item for a final time using the polling tool. Frequency percentages will be generated in real time and presented to the voters on-screen to facilitate discussion. The facilitator will guide further discussion regarding any items garnering equal consensus (50%) between the agreement ("essential" and "very important") and disagreement ("unimportant" and "not at all important") before asking participants to vote again. In all other cases, items failing to meet the predetermined ≥75% consensus score will be eliminated.

Reporting the Survey Results

To ensure a thorough description of the Delphi process, survey results will be reported following the Checklist for Reporting Results of Internet E-Surveys [142].

Objective 2: To Identify Critical Decision Points in the Care of People With DCM—Process Mapping the Patient Journey

Overview

Critical decision points in the trajectory of patients will be identified using process mapping, a technique that can aptly describe the workflow and cognitive procedures associated with an activity at the desired level of granularity [143]. We define a critical decision point as a distinct juncture in the care pathway when a professional-patient discussion leads to a care decision. These are essential "go-or-no-go" decisions [59]. Our process map protocol follows the quality criteria framework set out by Antonacci et al [69] to ensure compliance with best practice recommendations. Our approach to each phase is described in the following sections.

Preparation, Planning, and Process Identification

The process map exercise described in this protocol is guided by the need to characterize common critical decision points that adequately represent the global DCM health care pathway. To obtain broad insights, we define the starting point as the time when a person with DCM is diagnosed with DCM and the end point as the time when a person with DCM engages in posttreatment management of the condition. We will define the patient group under investigation as people with moderate or severe DCM treated surgically and people with mild DCM treated nonoperatively [2]. This approach will ensure an all-encompassing investigation of the care route for people with DCM.

Steering Group

It is good practice for process map exercises to be led by a steering group comprising at least one member with lived experience of the condition under investigation and a member with previous process map experience [144]. Following these recommendations, our process map activities will be supervised by the same multidisciplinary study committee overseeing the Delphi consensus process. At a minimum, the committee is envisaged to meet at the beginning and end of project activities, with further meetings as required. Decisions made at meetings will be binding when the meetings are quorate, that is, attended by at least one member of the core research team, one patient representative, and one member with process map experience. Project-relevant communications may also take place via email correspondence as necessary.

Recruitment Strategy and Skills Training

Key informants—English-speaking adults (aged ≥18 years)—will be drawn from the specialized RECODE-DCM community using a convenience sampling approach. Professionals will be approached for participation if they belong to key clinical disciplines, including spinal surgery, neurology, combined physical and psychological rehabilitation medicine, physiotherapy, pain management, and primary care [4,108], and have at least 5 years of experience in managing DCM. People with DCM will be eligible if they have undergone surgical decompressive treatment at least 6 months before, the time point at which neurological recovery is considered to halt [107], and if they have experienced the common care pathway for spinal disorders from primary care to rehabilitative services [145]. This criterion will ensure that participants with DCM are familiar with a wide range of interventions and services along the global spinal care pathway and, therefore, can provide an informed view of its workflow and cognitive decision points. To ensure a global representation of the spinal care workflows and cognitive decisions, both professionals and participants with DCM will be sought at the previously described geographical target ratio. In addition, a 1:1 ratio corresponding to HCPs to people with DCM will be sought in the development of the baseline process map.

An electronic study pack will be provided to those interested in participating, comprising a written study summary, this study protocol, and a Participant Information Sheet containing the study investigators' contact details. To equip respondents with

the necessary process map skills, all consenting participants will be issued a short explanatory document outlining relevant process map symbols alongside an example of a finalized map from a different health care process. Participants will be given the opportunity to contact the study team should they have any questions or require further clarification before commencing study activities.

Data Gathering

To enhance accessibility and foster participant engagement [146], data will be collected using one-to-one semistructured interviews, estimated at approximately 60 minutes and conducted via Google Meet. The interview schedules will be grounded in the literature, aiming to capture information on each step of routine clinical care under investigation [144,145]. To enhance comprehensiveness and incorporate expert input, the topic guide will undergo review and approval by the aforementioned steering group. In total, 2 distinct interview guides will be developed to interview clinicians and people with DCM. For clinicians, we propose a tailored approach in recognition of the specialization inherent in each HCP's role. For example, primary care physicians are instrumental in recognizing the condition and its associated clinical examinations for referral to a spinal surgeon [42]. Specialist surgeons, under the remit of neurosurgery or orthopedics, play a pivotal role in steering the course of management [147]. Specialist practitioners such as physiotherapists play a vital role in assisting in the management of DCM via preoperative physiotherapy and neurorehabilitation programs, primarily used in the context of DCM to manage disability postoperatively [40,148]. Therefore, our interview guide will account for differences in specialists' knowledge of care for DCM by asking HCPs an open question regarding how they manage people with DCM in their role specifically. From there, prompts relevant to each clinician's profession and based on the information they provide will be used to guide the interview. By grounding the topic schedule in the particularities of each professional's role, our approach can help ensure a thorough exploration of clinicians' perspectives, accounting for the nuanced differences across specialties and individual clinical roles within the DCM care pathway. We also recognize that the care pathways of people with DCM differ owing to variations in patients' DCM, flow times between different regions in the world, and guidelines of care [149]. Therefore, patients will be encouraged to share their experiences navigating the care system, focusing particularly on key decision-making points. Prompts will be used to elicit detailed accounts of their journey, the information sources they relied on, their understanding of their condition at each stage, and their level of satisfaction with the decision-making process. Interviews will be conducted until data saturation is reached, that is, until no new information is identified with respect to the research question [150]. At a minimum, it is envisaged that this will involve 20 interviews with HCPs and people with DCM. To allow for the incorporation of new insights generated during the data collection process, the interview guide may be adapted as necessary [151].

A baseline map will be developed by interviewing 3 surgeons and 3 people with DCM from each of the geographical target areas. This approach seeks to ensure that international perspectives are adequately represented from the onset. As surgical intervention is the cornerstone treatment for DCM and surgeons preponderate the research community [50], professional transcripts derived from surgeons specifically (rather than other HCPs) will inform the preliminary map. As women remain underrepresented in clinical surgical practice [152], we will seek to recruit the views of at least one female spinal or orthopedic surgeon in the development of the baseline map. This preliminary map will be developed iteratively through a series of additional interviews with surgeons, other HCPs, and people with DCM while ensuring geographical representation. Interviews will be audio recorded and written informed consent will be sought from all participants. Following their interview, each participant will be provided with a copy of their transcript, a process map created from their interview data, and the evolving baseline map. Participants will be asked to reflect on their interviews and consider whether they wish to supplement the process map. This approach will be used as a means of ensuring data validation and quality and promoting further unbiased contributions to the data [153,154].

Upon reaching data saturation, a selection of interviews will be chosen based on their richness, and the final process maps will be refined by referring to them. Data richness will be defined as "thick" data that best capture the multifaceted complexities of the process under investigation [155]. Participants will be assigned unique study numbers to anonymize their identities in the transcripts.

Map Generation

The baseline map will be developed and schematically represented using Lucidchart (Lucid Software Inc), a web-based diagramming application, and developed iteratively based on information obtained during subsequent interviews. A level of complexity associated with ad hoc variation in the international processes and cognitive decision points is anticipated. To accurately depict this, several process maps may need to be generated. For example, a separate process map may need to be created for preoperative, operative, and postoperative processes. Where possible, relevant clinical pathway documents provided by participants will be used in the development of the process map.

Data Analysis

Interviews will be transcribed verbatim and analyzed using inductive thematic analysis according to Braun and Clarke [156]. This will involve a coding process whereby segments of text are systematically organized according to common concepts and broader themes developed to encapsulate the main topics present in the interview data. The synthesis of these themes will be used to develop a visual representation of the interview data within the process map. The map will be developed iteratively, ensuring the inclusion of emerging themes. The final stage will involve validation to ensure the accuracy and reliability of the process map. This can be achieved through methods such as member checking, peer debriefing, or triangulation, ensuring the credibility and dependability of the findings [157]. The final process maps will be shared with the key participating stakeholders for comments and validation over email. Participant demographic characteristics will be collected during the

interviews and presented in tabular form using frequencies, means, and SDs as appropriate. For HCPs, demographic data will include age, gender, job title, a brief description of their duties, and number of years managing DCM. For people with DCM, this will include age, gender, occupation, year of diagnosis, and treatment (where applicable).

Future Steps

Process maps should be used to guide process improvement initiatives [158]. The process maps generated following this study protocol will inform future efforts by Myelopathy.org to develop SDM tools that will help people with DCM participate in making specific and deliberate choices regarding their health. In particular, at the time of writing this protocol, it is considered that identifying critical decision-making points will allow for the development of widely used evidence-based SDM tools such as patient decision aids [159-162] or patient road maps [28].

Ethics Approval

The University of Cambridge Human Biology Research Ethics Committee has approved the study (approval HBREC.2023.04).

Informed Consent, Data Protection, and Dissemination Strategies

Written informed consent will be sought from participants for both study objectives, that is, in the development of the CIS and process map exercise. All data will be handled under UK data protection regulations. Dissemination strategies for this project will include scientific publication and communication of findings via the Myelopathy.org website and Myelopathy Matters podcast.

Results

Recruitment for the Delphi consensus study began in April 2023. The pilot-testing of process map interview participants started simultaneously, with the formulation of an initial baseline map developed at the end of June 2023.

Discussion

The proposed study protocol outlines a Delphi consensus process that draws on the expertise of clinicians experienced in managing DCM and of people with DCM to formulate a diagnosis-specific CIS. It provides the rationale for undertaking an international process map exercise to characterize the common decision points in the health journey of people with DCM and outlines a strategy for generating outputs that aptly fit the needs of the global DCM community via broad stakeholder consultation.

Significance of the Study

To the best of our knowledge, this is the first initiative that aims to engage people with DCM in the management of their care. Given the high global incidence of DCM [2,163], the outputs of this preliminary study are relevant to a substantial cohort of people with DCM, clinicians, and policy makers worldwide. Most importantly, the CIS aims to address the significant educational deficit identified in DCM [38,45]. Drawing on the

tangible impact of structured patient education [164-169], we anticipate that the CIS has the potential to reduce knowledge discrepancies and advance equitable opportunities for quality health management decisions. In particular, as CISs are developed using key stakeholder input, they are ideally placed to facilitate a well-orchestrated communication that mitigates the biases or inadequacies associated with purely professional-led communication [60,63]. Furthermore, educating patients on the condition is one facet of improving their openness to and, arguably, time to surgery [45], potentially driving improvements in health care outcomes [170,171]. This is important as many people with DCM misunderstand the necessity and immediacy of surgery [45]. An appraisal of the CIS will be undertaken following its implementation to assess its efficacy in clinical practice.

In addition, we anticipate that the benefits of the process map in the international DCM care pathways may extend beyond SDM, for example, to addressing timely treatment and improving knowledge exchange [69]. Characterizing the key decision points and matching them to the current evidence base may expose critical knowledge gaps that must be served with targeted research. This means that, as the evidence is updated, so can be the SDM tool, helping accelerate the adoption of evidence into practice. In addition, providing a tangible visual tool to convey the patient experience across different health care settings and among various stakeholders may enhance communication among multidisciplinary teams [69], a recognized objective in DCM [172]. In the long run, the process map can serve as a valuable tool for patient advocacy, spotlighting areas of the care process that are particularly challenging [45], allowing policy makers and care providers to be better informed about the realities of living with DCM. This takes on added significance in low- and middle-income countries [173], where the burden of DCM is high yet access to care remains substandard [149]. Finally, developing a globally shared understanding of DCM care, with its similarities and differences, may facilitate opportunities for local redesign, development, or evaluation [69], leading to improvements in access to treatment [13].

Strengths and Limitations

The proposed study has several methodological strengths and limitations. First, the Delphi method offers an unbiased manner of soliciting consensus when this is lacking [174]. The guarantee of anonymity reduces expert-layperson power asymmetries between clinicians and patients, which are inherent in typical health care interactions [175]. This provision is particularly important to people with DCM, the beneficiaries of the CIS, to assert their viewpoints without reservation. Furthermore, the provision of systematic and controlled feedback fosters transparency, dialogue, learning, and sometimes novel insights that might not have been apparent in isolation [78]. Through its systematic progression, the Delphi method allows for gradual refinement of ideas [176]. Information items put forward for consensus in this manner are likely to become more patient-centric, relevant, and clear, ultimately resulting in the production of a more pertinent CIS. In addition, conducting the survey over the internet broadens the inclusion of people with

DCM, including presurgical DCM, which is poorly represented in the conventional literature [50,177].

This approach also has a number of limitations. Despite comprehensive efforts to source a broad range of expert participants, the conclusions of the study may suffer from limitations associated with the panel's composition. This is the case with any Delphi study [178]. In this regard, our purposive sampling approach may lead to outputs that may not fully reflect all health care contexts and stakeholders' perspectives. Pilot-testing the survey with a smaller representative sample can help ensure its comprehensiveness [179]. Expert judgment may also be influenced by cognitive biases, which is a well-recognized limitation of Delphi studies [79]. To mitigate this, we are curating an expert panel diverse in both roles and geographic locations to promote a more balanced collective judgment [180]. Other efforts to minimize bias throughout the Delphi process include the randomization of survey statements to eliminate primacy effects, requests to participants to include a rationale for their choices, and providing feedback in the form of median rather than mean values [116,124,125]. Compared with evidence-based approaches, expert surveys do not capture cause-effect relationships and are, therefore, definitive [181]. That is, our experts' agreement on the final CIS does not assure the tool's efficacy. To address this concern, the CIS will be evaluated, the specifics of which will be laid out in a separate study protocol.

Finally, inductive thematic analysis provides an adaptable methodology for developing the process map. Its flexibility allows for the generation of unanticipated themes and patterns [156]. Coding and organizing the data around common concepts aids in translating potentially complex data into a digestible visual representation [182]. The iterative nature of this method allows for continuous refinement of the process map, thereby increasing the reliability of the results [183], whereas validation strategies such as member checking and peer debriefing ensure the accuracy, credibility, and dependability of the findings [157].

Conclusions

This is the first study to establish an international-led collaborative framework aimed at enabling SDM in the management of a chronic illness. To the best of our knowledge, this approach has not been used before. The projected benefits of this initiative are poised to improve people with DCM's knowledge about their condition. In the long term, this study is intended to drive the development and deployment of SDM tools in DCM care.

Acknowledgments

Data Availability

The data sets being generated and analyzed in this ongoing study are not publicly available at this time because of the need to preserve the integrity of the ongoing Delphi consensus process but will be shared in subsequent publications after the study concludes.

Authors' Contributions

BMD contributed to conceptualization, funding acquisition, supervision, original draft preparation, and review and editing. BG contributed to conceptualization, methodology, and funding acquisition. IS contributed to conceptualization, methodology, original draft preparation, and review and editing. GA contributed to conceptualization, methodology, draft preparation, and review and editing. AM contributed to methodology, draft preparation, and review and editing. The other authors contributed to review and editing.

Conflicts of Interest

MRNK is a trustee of the Myelopathy.org charity.

Multimedia Appendix 1

Word cloud of qualitative codes generated from the thematic analysis of interviews with people with degenerative cervical myelopathy.
[PNG File , 279 KB-Multimedia Appendix 1]

References

1. 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 2022 Jun 29:21925682221111780 (forthcoming) [FREE Full text] [doi: 10.1177/21925682221111780] [Medline: 35769029]

2. Davies BM, Mowforth OD, Smith EK, Kotter MR. Degenerative cervical myelopathy. BMJ 2018 Feb 22;360:k186 [FREE Full text] [doi: 10.1136/bmj.k186] [Medline: 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. Global Spine J 2022 Feb 17;12(1_suppl):78S-96S [FREE Full text] [doi: 10.1177/21925682211057546] [Medline: 35174728]

4. Davies BM, Khan DZ, Mowforth OD, McNair AG, Gronlund T, Kolias AG, et al. RE-CODE DCM (search Objectives and ommon ata lements for egenerative ervical yelopathy): 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 08;9(1 Suppl):65S-76S [FREE Full text] [doi: 10.1177/2192568219832855] [Medline: 31157148]

5. Grodzinski B, Stubbs DJ, Davies BM. Most degenerative cervical myelopathy remains undiagnosed, particularly amongst the elderly: modelling the prevalence of degenerative cervical myelopathy in the United Kingdom. J Neurol 2023 Jan 02;270(1):311-319 [FREE Full text] [doi: 10.1007/s00415-022-11349-8] [Medline: 36056204]

6. Badhiwala JH, Witiw CD, Nassiri F, Akbar MA, Mansouri A, Wilson JR, et al. Efficacy and safety of surgery for mild degenerative cervical myelopathy: results of the AOSpine North America and International Prospective Multicenter Studies. Neurosurgery 2019 Apr 01;84(4):890-897 [FREE Full text] [doi: 10.1093/neuros/nyy133] [Medline: 29684181]

7. Gulati S, Vangen-Lønne V, Nygaard Ø, Gulati AM, Hammer TA, Johansen TO, et al. Surgery for degenerative cervical myelopathy: a nationwide registry-based observational study with patient-reported outcomes. Neurosurgery 2021 Sep 15;89(4):704-711 [FREE Full text] [doi: 10.1093/neuros/nyab259] [Medline: 34325471]

8. 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. Spine 2015 Sep 1;40(17):1322-1328 [doi: 10.1097/brs.0000000000000988]

9. Boerger TF, Davies BM, Sadler I, Sarewitz E, Kotter MR. Patient, sufferer, victim, casualty or person with cervical myelopathy: let us decide our identifier. Integr Healthc J 2020 Jun 25;2(1):e000023 [doi: 10.1136/ihj-2019-000023]

10. Khan DZ, Fitzpatrick SM, Hilton B, McNair AG, Sarewitz E, Davies BM, AO Spine Knowledge Forum Spinal Cord Injury. Prevailing outcome themes reported by people with degenerative cervical myelopathy: focus group study. JMIR Form Res 2021 Feb 03;5(2):e18732 [FREE Full text] [doi: 10.2196/18732] [Medline: 33533719]

11. Hirayama Y, Mowforth OD, Davies BM, Kotter MR. Determinants of quality of life in degenerative cervical myelopathy: a systematic review. Br J Neurosurg 2023 Feb 18;37(1):71-81 [doi: 10.1080/02688697.2021.1999390] [Medline: 34791981]

12. Stoffman MR, Roberts MS, King JT. Cervical spondylotic myelopathy, depression, and anxiety: a cohort analysis of 89 patients. Neurosurgery 2005 Aug;57(2):307-13; discussion 307 [doi: 10.1227/01.neu.0000166664.19662.43] [Medline: 16094160]

13. Pope DH, Mowforth OD, Davies BM, Kotter MR. Diagnostic delays lead to greater disability in degenerative cervical myelopathy and represent a health inequality. Spine (Phila Pa 1976) 2020 Mar 15;45(6):368-377 [doi: 10.1097/BRS.0000000000003305] [Medline: 31658234]

14. 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 [doi: 10.1016/j.wneu.2016.12.124] [Medline: 28065875]

15. Davies BM, Phillips R, Clarke D, Furlan JC, Demetriades AK, Milligan J, et al. Establishing the socio-economic impact of degenerative cervical myelopathy is fundamental to improving outcomes [AO Spine RECODE-DCM research priority number 8]. Global Spine J 2022 Feb 17;12(1_suppl):122S-129S [FREE Full text] [doi: 10.1177/21925682211039835] [Medline: 35174730]

16. 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 07;8(4):e12381 [FREE Full text] [doi: 10.2196/12381] [Medline: 31697240]

17. The Lancet Neurology. A focus on patient outcomes in cervical myelopathy. Lancet Neurol 2019 Jul;18(7):615 [FREE Full text] [doi: 10.1016/s1474-4422(19)30168-1]

18. Davies BM, Kwon BK, Fehlings MG, Kotter MR. AO Spine RECODE-DCM: why prioritize research in degenerative cervical myelopathy? Global Spine J 2022 Feb 17;12(1_suppl):5S-7S [FREE Full text] [doi: 10.1177/21925682211035379] [Medline: 35174732]

19. Adams R. Improving health outcomes with better patient understanding and education. Risk Manag Healthc Policy 2010 Oct 14;3:61-72 [doi: 10.2147/rmhp.s7500]

20. Husson O, Thong MS, Mols F, Smilde TJ, Creemers GJ, van de Poll-Franse LV. Information provision and patient reported outcomes in patients with metastasized colorectal cancer: results from the PROFILES registry. J Palliat Med 2013 Mar;16(3):281-288 [FREE Full text] [doi: 10.1089/jpm.2012.0430] [Medline: 23437833]

21. Rasu RS, Bawa WA, Suminski R, Snella K, Warady B. Health literacy impact on national healthcare utilization and expenditure. Int J Health Policy Manag 2015 Aug 17;4(11):747-755 [FREE Full text] [doi: 10.15171/ijhpm.2015.151] [Medline: 26673335]

22. Vandenbosch J, Van den Broucke S, Vancorenland S, Avalosse H, Verniest R, Callens M. Health literacy and the use of healthcare services in Belgium. J Epidemiol Community Health 2016 Oct;70(10):1032-1038 [doi: 10.1136/jech-2015-206910] [Medline: 27116951]

23. Wieringa TH, Rodriguez-Gutierrez R, Spencer-Bonilla G, de Wit M, Ponce OJ, Sanchez-Herrera MF, et al. Decision aids that facilitate elements of shared decision making in chronic illnesses: a systematic review. Syst Rev 2019 May 20;8(1):121 [FREE Full text] [doi: 10.1186/s13643-019-1034-4] [Medline: 31109357]

24. Carmona C, Crutwell J, Burnham M, Polak L, Guideline Committee. Shared decision-making: summary of NICE guidance. BMJ 2021 Jun 17;373:n1430 [doi: 10.1136/bmj.n1430] [Medline: 34140279]

25. Elwyn G, Cochran N, Pignone M. Shared decision making-the importance of diagnosing preferences. JAMA Intern Med 2017 Sep 01;177(9):1239-1240 [doi: 10.1001/jamainternmed.2017.1923] [Medline: 28692733]

26. Desroches S. Shared decision making and chronic diseases. All Asth Clin Immun 2010 Dec 10;6(S4):A8 [doi: 10.1186/1710-1492-6-s4-a8]

27. Gionfriddo MR, Leppin AL, Brito JP, Leblanc A, Boehmer KR, Morris MA, et al. A systematic review of shared decision making interventions in chronic conditions: a review protocol. Syst Rev 2014 Apr 15;3(1):38 [FREE Full text] [doi: 10.1186/2046-4053-3-38] [Medline: 24731616]

28. Scherer LD, Matlock DD, Allen LA, Knoepke CE, McIlvennan CK, Fitzgerald MD, et al. Patient roadmaps for chronic illness: introducing a new approach for fostering patient-centered care. MDM Policy Pract 2021 Jul 02;6(1):23814683211019947 [FREE Full text] [doi: 10.1177/23814683211019947] [Medline: 34277949]

29. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract 2001;4(6):256-262 [Medline: 11769298]

30. O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR, et al. Toward the 'tipping point': decision aids and informed patient choice. Health Aff (Millwood) 2007 May;26(3):716-725 [doi: 10.1377/hlthaff.26.3.716] [Medline: 17485749]

31. Lubkin IM, Larsen PD. Chronic Illness: Impact and Intervention Eighth Edition. Burlington, MA: Jones & Bartlett Learning; 2013.

32. Lasorsa I, D'Antrassi P, Ajčević M, Stellato K, Di Lenarda A, Marceglia S, et al. Personalized support for chronic conditions. Appl Clin Inform 2017 Dec 19;07(03):633-645 [doi: 10.4338/aci-2016-01-ra-0011]

33. Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. Health Expect 2006 Mar;9(1):25-36 [FREE Full text] [doi: 10.1111/j.1369-7625.2006.00359.x] [Medline: 16436159]

34. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? BMJ 1999 Sep 18;319(7212):780-782 [FREE Full text] [doi: 10.1136/bmj.319.7212.780] [Medline: 10488014]

35. Devine EC, Cook TD. A meta-analytic analysis of effects of psychoeducational interventions on length of postsurgical hospital stay. Nurs Res 1983;32(5):267-274 [doi: 10.1097/00006199-198309000-00003]

36. Kaplan SH, Greenfield S, Ware JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med Care 1989 Mar;27(3 Suppl):S110-S127 [doi: 10.1097/00005650-198903001-00010] [Medline: 2646486]

37. Khan O, Badhiwala JH, Grasso G, Fehlings MG. Use of machine learning and artificial intelligence to drive personalized medicine approaches for spine care. World Neurosurg 2020 Aug;140:512-518 [doi: 10.1016/j.wneu.2020.04.022] [Medline: 32797983]

38. Umeria R, Mowforth O, Grodzinski B, Karimi Z, Sadler I, Wood H, et al. A scoping review of information provided within degenerative cervical myelopathy education resources: towards enhancing shared decision making. PLoS One 2022 May 19;17(5):e0268220 [FREE Full text] [doi: 10.1371/journal.pone.0268220] [Medline: 35588126]

39. Davies BM, Munro CF, Kotter MR. A novel insight into the challenges of diagnosing degenerative cervical myelopathy using web-based symptom checkers. J Med Internet Res 2019 Jan 11;21(1):e10868 [FREE Full text] [doi: 10.2196/10868] [Medline: 30300137]

40. Rhee J, Tetreault LA, Chapman JR, Wilson JR, Smith JS, Martin AR, et al. Nonoperative versus operative management for the treatment degenerative cervical myelopathy: an updated systematic review. Global Spine J 2017 Sep 05;7(3 Suppl):35S-41S [FREE Full text] [doi: 10.1177/2192568217703083] [Medline: 29164031]

41. Kato S, Ganau M, Fehlings MG. Surgical decision-making in degenerative cervical myelopathy - anterior versus posterior approach. J Clin Neurosci 2018 Dec;58:7-12 [doi: 10.1016/j.jocn.2018.08.046] [Medline: 30279123]

42. Milligan J, Ryan K, Fehlings M, Bauman C. Degenerative cervical myelopathy: diagnosis and management in primary care. Can Fam Physician 2019 Sep;65(9):619-624 [FREE Full text] [Medline: 31515310]

43. 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 05;9(5):e027000 [FREE Full text] [doi: 10.1136/bmjopen-2018-027000] [Medline: 31061045]

44. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. J Gen Intern Med 2012 Oct;27(10):1361-1367 [FREE Full text] [doi: 10.1007/s11606-012-2077-6] [Medline: 22618581]

45. Sangeorzan I, Andriopoulou P, Davies BM, McNair A. The information needs of people with degenerative cervical myelopathy: a qualitative study to inform patient education in clinical practice. PLoS One 2023 May 19;18(5):e0285334 [FREE Full text] [doi: 10.1371/journal.pone.0285334] [Medline: 37205664]

46. Davis D, Evans M, Jadad A, Perrier L, Rath D, Ryan D, et al. The case for knowledge translation: shortening the journey from evidence to effect. BMJ 2003 Jul 05;327(7405):33-35 [FREE Full text] [doi: 10.1136/bmj.327.7405.33] [Medline: 12842955]

47. Wensing M, Grol R. Knowledge translation in health: how implementation science could contribute more. BMC Med 2019 May 07;17(1):88 [FREE Full text] [doi: 10.1186/s12916-019-1322-9] [Medline: 31064388]

48. 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 Feb 17;12(1_suppl):28S-38S [FREE Full text] [doi: 10.1177/21925682211050927] [Medline: 35174734]

49. Fehlings MG, Tetreault LA, Riew KD, Middleton JW, Aarabi B, Arnold PM, et al. A clinical practice guideline for the management of patients with degenerative cervical myelopathy: recommendations for patients with mild, moderate, and severe disease and nonmyelopathic patients with evidence of cord compression. Global Spine J 2017 Sep;7(3 Suppl):70S-83S [FREE Full text] [doi: 10.1177/2192568217701914] [Medline: 29164035]

50. Mowforth OD, Davies BM, Goh S, O'Neill CP, Kotter MR. Research inefficiency in degenerative cervical myelopathy: findings of a systematic review on research activity over the past 20 years. Global Spine J 2020 Jun 12;10(4):476-485 [FREE Full text] [doi: 10.1177/2192568219847439] [Medline: 32435569]

51. Tempest-Mitchell J, Hilton B, Davies BM, Nouri A, Hutchinson PJ, Scoffings DJ, et al. A comparison of radiological descriptions of spinal cord compression with quantitative measures, and their role in non-specialist clinical management. PLoS One 2019 Jul 22;14(7):e0219380 [FREE Full text] [doi: 10.1371/journal.pone.0219380] [Medline: 31329621]

52. Nouri A, Tetreault L, Dalzell K, Zamorano JJ, Fehlings MG. The relationship between preoperative clinical presentation and quantitative magnetic resonance imaging features in patients with degenerative cervical myelopathy. Neurosurgery 2017 Jan 01;80(1):121-128 [doi: 10.1227/NEU.0000000000001420] [Medline: 27607403]

53. Hilton B, Tempest-Mitchell J, Davies BM, Francis J, Mannion RJ, Trivedi R, et al. Cord compression defined by MRI is the driving factor behind the decision to operate in Degenerative Cervical Myelopathy despite poor correlation with disease severity. PLoS One 2019 Dec 26;14(12):e0226020 [FREE Full text] [doi: 10.1371/journal.pone.0226020] [Medline: 31877151]

54. Banner D, Bains M, Carroll S, Kandola DK, Rolfe DE, Wong C, et al. Patient and public engagement in integrated knowledge translation research: are we there yet? Res Involv Engagem 2019 Feb 12;5:8 [FREE Full text] [doi: 10.1186/s40900-019-0139-1] [Medline: 30805202]

55. Straus SE, Tetroe J, Graham I. Defining knowledge translation. CMAJ 2009 Aug 04;181(3-4):165-168 [FREE Full text] [doi: 10.1503/cmaj.081229] [Medline: 19620273]

56. Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. Lancet 2003 Oct 11;362(9391):1225-1230 [doi: 10.1016/S0140-6736(03)14546-1] [Medline: 14568747]

57. Eljiz K, Greenfield D, Hogden A, Taylor R, Siddiqui N, Agaliotis M, et al. Improving knowledge translation for increased engagement and impact in healthcare. BMJ Open Qual 2020 Sep 17;9(3):e000983 [FREE Full text] [doi: 10.1136/bmjoq-2020-000983] [Medline: 32943430]

58. Wofford JL, Smith ED, Miller DP. The multimedia computer for office-based patient education: a systematic review. Patient Educ Couns 2005 Nov;59(2):148-157 [doi: 10.1016/j.pec.2004.10.011] [Medline: 16257619]

59. Whichello C, Bywall KS, Mauer J, Stephen W, Cleemput I, Pinto CA, et al. An overview of critical decision-points in the medical product lifecycle: where to include patient preference information in the decision-making process? Health Policy 2020 Dec;124(12):1325-1332 [FREE Full text] [doi: 10.1016/j.healthpol.2020.07.007] [Medline: 32839011]

60. Main BG, McNair AG, Haworth S, Rooshenas L, Hughes CW, Tierney P, et al. Core information set for informed consent to surgery for oral or oropharyngeal cancer: a mixed-methods study. Clin Otolaryngol 2018 Apr 21;43(2):624-631 [doi: 10.1111/coa.13037] [Medline: 29178168]

61. Blazeby JM, Macefield R, Blencowe NS, Jacobs M, McNair AG, Sprangers M, Research Group of the Core OutcomesiNformation SEts iN SUrgical Studies-Oesophageal Cancer, Consensus Group of the Core OutcomesiNformation SEts iN SUrgical Studies-Oesophageal Cancer. Core information set for oesophageal cancer surgery. Br J Surg 2015 Jul;102(8):936-943 [doi: 10.1002/bjs.9840] [Medline: 25980524]

62. McNair AG, Whistance RN, Main B, Forsythe R, Macefield R, Rees J, et al. Development of a core information set for colorectal cancer surgery: a consensus study. BMJ Open 2019 Nov 14;9(11):e028623 [FREE Full text] [doi: 10.1136/bmjopen-2018-028623] [Medline: 31727644]

63. Main BG, McNair AG, Huxtable R, Donovan JL, Thomas SJ, Kinnersley P, et al. Core information sets for informed consent to surgical interventions: baseline information of importance to patients and clinicians. BMC Med Ethics 2017 Apr 26;18(1):29 [FREE Full text] [doi: 10.1186/s12910-017-0188-7] [Medline: 28446164]

64. Tariman JD, Doorenbos A, Schepp KG, Singhal S, Berry DL. Information needs priorities in patients diagnosed with cancer: a systematic review. J Adv Pract Oncol 2014;2014(5):115-122 [FREE Full text] [Medline: 24910808]

65. Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. Health Aff (Millwood) 2013 Feb;32(2):276-284 [doi: 10.1377/hlthaff.2012.1078] [Medline: 23381520]

66. McLaughlin N, Rodstein J, Burke MA, Martin NA. Demystifying process mapping: a key step in neurosurgical quality improvement initiatives. Neurosurgery 2014 Aug;75(2):99-109; discussion 109 [doi: 10.1227/NEU.0000000000000360] [Medline: 24681644]

67. Swann J. Process mapping: looking at the patient's full journey. Br J Healthc Assist 2017 Apr 02;11(4):196-200 [doi: 10.12968/bjha.2017.11.4.196]

68. Improvement leaders' guide: process mapping, analysis and redesign. National Health Service Institute for Innovation and Improvement. 2005. URL: http:england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/ILG-1. 2-Process-Mapping-Analysis-and-Redesign.pdf [accessed 2023-02-08]

69. Antonacci G, Lennox L, Barlow J, Evans L, Reed J. Process mapping in healthcare: a systematic review. BMC Health Serv Res 2021 Apr 14;21(1):342 [FREE Full text] [doi: 10.1186/s12913-021-06254-1] [Medline: 33853610]

70. Heher YK, Chen Y. Process mapping: a cornerstone of quality improvement. Cancer Cytopathol 2017 Dec 22;125(12):887-890 [FREE Full text] [doi: 10.1002/cncy.21946] [Medline: 29165909]

71. S2 Ep5 - education and myelopathy - knowledge is power? Apple Podcasts. URL: https://podcasts.apple.com/gb/podcast/ s2-ep5-education-myelopathy-knowledge-is-power/id1493647316?i=1000525442039 [accessed 2023-02-08]

72. Davies BM, Yanez Touzet A, Mowforth OD, Lee KS, Khan D, Furlan JC, AO Spine RECODE-DCM Steering Committee. Development of a core measurement set for research in degenerative cervical myelopathy: a study protocol (AO Spine RECODE-DCM CMS). BMJ Open 2022 Jun 09;12(6):e060436 [FREE Full text] [doi: 10.1136/bmjopen-2021-060436] [Medline: 35680260]

73. Khan DZ, Hazenbiller O, Gronlund T, Sadler I, Sarewitz EB, Mowforth O, et al. The AO Spine RECODE-DCM international collaborative-establishing the foundations for accelerated and patient-centered innovation. Global Spine J 2022 Feb 17;12(1_suppl):159S-171S [FREE Full text] [doi: 10.1177/21925682211035381] [Medline: 35174727]

74. Grodzinski N, Grodzinski B, Davies BM. Can co-authorship networks be used to predict author research impact? A machine-learning based analysis within the field of degenerative cervical myelopathy research. PLoS One 2021 Sep 2;16(9):e0256997 [FREE Full text] [doi: 10.1371/journal.pone.0256997] [Medline: 34473796]

75. Grodzinski B, Bestwick H, Bhatti F, Durham R, Khan M, Partha Sarathi CI, et al. Research activity amongst DCM research priorities. Acta Neurochir (Wien) 2021 Jun 24;163(6):1561-1568 [FREE Full text] [doi: 10.1007/s00701-021-04767-6] [Medline: 33625603]

76. Regnault A, Willgoss T, Barbic S, International Society for Quality of Life Research (ISOQOL) Mixed Methods Special Interest Group (SIG). Towards the use of mixed methods inquiry as best practice in health outcomes research. J Patient Rep Outcomes 2017 Apr 11;2(1):19 [FREE Full text] [doi: 10.1186/s41687-018-0043-8] [Medline: 29757311]

77. Barrett D, Heale R. What are Delphi studies? Evid Based Nurs 2020 Jul 19;23(3):68-69 [doi: 10.1136/ebnurs-2020-103303] [Medline: 32430290]

78. Linstone HA, Turoff M. The Delphi Method: Techniques and Applications. Boston, MA: Addison-Wesley; 1975.

79. Okoli C, Pawlowski SD. The Delphi method as a research tool: an example, design considerations and applications. Inf Manag 2004 Dec;42(1):15-29 [doi: 10.1016/j.im.2003.11.002]

80. Hsu CC, Sandford BA. The Delphi technique: making sense of consensus. Pract Assess Res Eval 2007;12(10):1-8 [FREE Full text]

81. Holey EA, Feeley JL, Dixon J, Whittaker VJ. An exploration of the use of simple statistics to measure consensus and stability in Delphi studies. BMC Med Res Methodol 2007 Nov 29;7(1):52 [FREE Full text] [doi: 10.1186/1471-2288-7-52] [Medline: 18045508]

82. Cantrill JA, Sibbald B, Buetow S. The Delphi and nominal group techniques in health services research. Int J Pharm Pract 2011;4(2):67-74 [doi: 10.1111/j.2042-7174.1996.tb00844.x]

83. Jorm AF. Using the Delphi expert consensus method in mental health research. Aust N Z J Psychiatry 2015 Oct 21;49(10):887-897 [doi: 10.1177/0004867415600891] [Medline: 26296368]

84. van Hasselt FM, Oud MJ, Loonen AJ. Practical recommendations for improvement of the physical health care of patients with severe mental illness. Acta Psychiatr Scand 2015 May 11;131(5):387-396 [doi: 10.1111/acps.12372] [Medline: 25495118]

85. Negrini S, Armijo-Olivo S, Patrini M, Frontera WR, Heinemann AW, Machalicek W, RCTRACK Promoters. The randomized controlled trials rehabilitation checklist: methodology of development of a reporting guideline specific to rehabilitation. Am J Phys Med Rehabil 2020 Mar 17;99(3):210-215 [FREE Full text] [doi: 10.1097/PHM.0000000000001370] [Medline: 31851008]

86. Jünger S, Payne S, Brearley S, Ploenes V, Radbruch L. Consensus building in palliative care: a Europe-wide delphi study on common understandings and conceptual differences. J Pain Symptom Manage 2012 Aug;44(2):192-205 [FREE Full text] [doi: 10.1016/j.jpainsymman.2011.09.009] [Medline: 22704058]

87. Ambrosiadou BV, Goulis DG. The DELPHI method as a consensus and knowledge acquisition tool for the evaluation of the DIABETES system for insulin administration. Med Inform Internet Med 1999 Jul 12;24(4):257-268 [doi: 10.1080/146392399298285] [Medline: 10674417]

88. Fadini GP, Disoteo O, Candido R, Di Bartolo P, Laviola L, Consoli A. Delphi-based consensus on treatment intensification in type 2 diabetes subjects failing basal insulin supported oral treatment: focus on basal insulin + GLP-1 receptor agonist combination therapies. Diabetes Ther 2021 Mar 07;12(3):781-800 [FREE Full text] [doi: 10.1007/s13300-021-01012-2] [Medline: 33550569]

89. Sarrió RG, Calsina-Berna A, García AG, Esparza-Miñana JM, Ferrer EF, Working Group ActEIO Project, et al. Delphi consensus on strategies in the management of opioid-induced constipation in cancer patients. BMC Palliat Care 2021 Jan 02;20(1):1 [FREE Full text] [doi: 10.1186/s12904-020-00693-z] [Medline: 33388041]

90. Massey PR, Schmults CD, Li SJ, Arron ST, Asgari MM, Bouwes Bavinck JN, et al. Consensus-based recommendations on the prevention of squamous cell carcinoma in solid organ transplant recipients: a Delphi consensus statement. JAMA Dermatol 2021 Oct 01;157(10):1219-1226 [FREE Full text] [doi: 10.1001/jamadermatol.2021.3180] [Medline: 34468690]

91. Jackson DJ, Butler C, Chaudhuri R, Pink K, Niven R, Prigmore S, et al. Recommendations following a modified UK-Delphi consensus study on best practice for referral and management of severe asthma. BMJ Open Respir Res 2021 Sep 28;8(1):e001057 [FREE Full text] [doi: 10.1136/bmjresp-2021-001057] [Medline: 34583985]

92. Caporali R, Carletto A, Conti F, D'Angelo S, Foti R, Gremese E, et al. Using a modified Delphi process to establish clinical consensus for the diagnosis, risk assessment and abatacept treatment in patients with aggressive rheumatoid arthritis. Clin Exp Rheumatol 2017;35(5):772-776 [Medline: 28281459]

93. Shi Z, Michalovic E, McKay R, Gainforth HL, McBride CB, Clarke T, et al. Outcomes of spinal cord injury peer mentorship: a community-based Delphi consensus approach. Ann Phys Rehabil Med 2023 Feb;66(1):101678 [doi: 10.1016/j.rehab.2022.101678] [Medline: 35659583]

94. van Schaik TJ, Pouw MH, Curt A, van Nes IJ, Vos-van der Hulst M, van Hooff ML. Standard set of network outcomes for traumatic spinal cord injury: a consensus-based approach using the Delphi method. Spinal Cord 2022 Sep 24;60(9):789-798 [doi: 10.1038/s41393-022-00792-z] [Medline: 35332273]

95. Akins RB, Tolson H, Cole BR. Stability of response characteristics of a Delphi panel: application of bootstrap data expansion. BMC Med Res Methodol 2005 Dec 01;5(1):37 [FREE Full text] [doi: 10.1186/1471-2288-5-37] [Medline: 16321161]

96. Powell C. The Delphi technique: myths and realities. J Adv Nurs 2003 Feb;41(4):376-382 [doi: 10.1046/j.1365-2648.2003.02537.x] [Medline: 12581103]

97. Beretta R. A critical review of the Delphi technique. Nurse Res 1996 Jun 01;3(4):79-89 [doi: 10.7748/nr.3.4.79.s8] [Medline: 27285530]

98. Keeney SH, McKenna HP, Hasson F. The Delphi Technique in Nursing and Health Research. Hoboken, NJ: Wiley; 2011.

99. Fink A, Kosecoff J, Chassin M, Brook RH. Consensus methods: characteristics and guidelines for use. Am J Public Health 1984 Sep;74(9):979-983 [doi: 10.2105/ajph.74.9.979] [Medline: 6380323]

100. Murry JW, Hammons JO. Delphi: a versatile methodology for conducting qualitative research. Rev Higher Educ 1995;18(4):423-436 [doi: 10.1353/rhe.1995.0008]

101. Clayton MJ. Delphi: a technique to harness expert opinion for critical decision‐making tasks in education. Educ Psychol 1997;17(4):373-386 [doi: 10.1080/0144341970170401]

102. Parente R, Anderson-Parente J. A case study of long-term Delphi accuracy. Technol Forecast Soc Change 2011 Nov;78(9):1705-1711 [doi: 10.1016/j.techfore.2011.07.005]

103. Spencer‐Cooke B. Conditions of participation in rural, non‐formal education programmes: a Delphi study. Educ Media Int 1989 Jun;26(2):115-124 [doi: 10.1080/0952398890260211]

104. Novakowski N, Wellar B. Using the Delphi technique in normative planning research: methodological design considerations. Environ Plan A 2009 Jan 01;40(6):1485-1500 [doi: 10.1068/a39267]

105. Wheeller B, Hart T, Whysall P. Application of the Delphi technique: a reply to Green, Hunter and Moore. Tour Manag 1990 Jun;11(2):121-122 [FREE Full text] [doi: 10.1016/0261-5177(90)90027-7]

106. Gordon TJ. The methods of futures research. Ann Am Acad Pol Soc Sci 2016 Sep 08;522(1):25-35 [doi: 10.1177/0002716292522001003]

107. Cheung WY, Arvinte D, Wong YW, Luk KD, Cheung KM. Neurological recovery after surgical decompression in patients with cervical spondylotic myelopathy - a prospective study. Int Orthop 2008 Apr 19;32(2):273-278 [FREE Full text] [doi: 10.1007/s00264-006-0315-4] [Medline: 17235616]

108. Chalmers I, Bracken MB, Djulbegovic B, Garattini S, Grant J, Gülmezoglu AM, et al. How to increase value and reduce waste when research priorities are set. Lancet 2014 Jan 11;383(9912):156-165 [doi: 10.1016/S0140-6736(13)62229-1] [Medline: 24411644]

109. Kiefer L, Frank J, Di Ruggiero E, Dobbins M, Manuel D, Gully PR, et al. Fostering evidence-based decision-making in Canada: examining the need for a Canadian population and public health evidence centre and research network. Can J Public Health 2005;96(3):I1-40 following 200 [Medline: 15913085]

110. White J, Patel V, Herrman H. Australian and New Zealand contribution to international mental health research publications: a survey of high-impact journals. World Psychiatry 2007 Feb;6(1):49-53 [FREE Full text] [Medline: 17342227]

111. Roulstone A, Hudson V. Carer participation in England, Wales and Northern Ireland: a challenge for interprofessional working. J Interprof Care 2007 Jun 06;21(3):303-317 [doi: 10.1080/13561820701327822] [Medline: 17487708]

112. Henderson EJ, Rubin GP. Development of a community-based model for respiratory care services. BMC Health Serv Res 2012 Jul 09;12(1):193 [FREE Full text] [doi: 10.1186/1472-6963-12-193] [Medline: 22776670]

113. Davies BM, Munro C, Khan DZ, Fitzpatrick SM, Hilton B, Mowforth OD, et al. Outcomes of degenerative cervical myelopathy from the perspective of persons living with the condition: findings of a semistructured interview process with partnered internet survey. Global Spine J 2022 Apr 18;12(3):432-440 [FREE Full text] [doi: 10.1177/2192568220953811] [Medline: 33203262]

114. Developing a patient education tool for DCM using the Delphi method. YouTube. URL: https://www.youtube.com/watch?v=VqoA8WLNI18&t=16s [accessed 2023-03-21]

115. Tracy SJ. Qualitative quality: eight "big-tent" criteria for excellent qualitative research. Qual Inquiry 2010 Oct 01;16(10):837-851 [doi: 10.1177/1077800410383121]

116. Singer E, Couper MP. Some methodological uses of responses to open questions and other verbatim comments in quantitative surveys. Methods Data Analyses 2017;11(2) [doi: 10.12758/mda.2017.01]

117. Bletzer KV. Visualizing the qualitative: making sense of written comments from an evaluative satisfaction survey. J Educ Eval Health Prof 2015 Apr 16;12:12 [FREE Full text] [doi: 10.3352/jeehp.2015.12.12] [Medline: 25959652]

118. Davies BM, Mowforth OD, Khan DZ, Yang X, Stacpoole SR, Hazenbiller O, et al. The development of lived experience-centered word clouds to support research uncertainty gathering in degenerative cervical myelopathy: results from an engagement process and protocol for their evaluation, via a nested randomized controlled trial. Trials 2021 Jun 25;22(1):415 [FREE Full text] [doi: 10.1186/s13063-021-05349-8] [Medline: 34172080]

119. Mowforth OD, Burn L, Khan DZ, Yang X, Stacpoole SR, Gronlund T, et al. Lived experience-centred word clouds may improve research uncertainty gathering in priority setting partnerships. BMC Med Res Methodol 2023 Apr 22;23(1):100 [FREE Full text] [doi: 10.1186/s12874-023-01897-6] [Medline: 37087419]

120. Reyes-Foster BM, DeNoyelles A. Influence of word clouds on critical thinking in online discussions: a content analysis. J Teach Learn Technol 2016 Jul 01;5(1):16-32 [doi: 10.14434/jotlt.v5n1.13805]

121. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. J Adv Nurs 2000 Oct;32(4):1008-1015 [doi: 10.1046/j.1365-2648.2000.t01-1-01567.x]

122. Nulty DD. The adequacy of response rates to online and paper surveys: what can be done? Assess Eval High Educ 2008 Jun;33(3):301-314 [doi: 10.1080/02602930701293231]

123. Garcia J, Evans J, Reshaw M. ``Is there anything else you would like to tell us'' – methodological issues in the use of free-text comments from postal surveys. Qual Quant 2004 Apr;38(2):113-125 [doi: 10.1023/b:ququ.0000019394.78970.df]

124. Hallowell M. Techniques to minimize bias when using the Delphi method to quantify construction safety and health risks. In: Proceedings of the Construction Research Congress 2009. 2009 Presented at: Construction Research Congress 2009; April 5-7, 2009; Seattle, WA [doi: 10.1061/41020(339)151]

125. Best RJ. An experiment in Delphi estimation in marketing decision making. J Market Res 1974 Nov;11(4):448-452 [doi: 10.2307/3151295]

126. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115 [doi: 10.1111/j.1365-2648.2007.04569.x] [Medline: 18352969]

127. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. Nurs Health Sci 2013 Sep 11;15(3):398-405 [doi: 10.1111/nhs.12048] [Medline: 23480423]

128. Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenge in interpretive description. Int J Qual Methods 2016 Nov 29;3(1):1-11 [doi: 10.1177/160940690400300101]

129. Mishra P, Pandey CM, Singh U, Gupta A. Scales of measurement and presentation of statistical data. Ann Card Anaesth 2018;21(4):419-422 [FREE Full text] [doi: 10.4103/aca.ACA_131_18] [Medline: 30333338]

130. Sim J, Wright CC. The Kappa statistic in reliability studies: use, interpretation, and sample size requirements. Phys Ther 2005 Mar 1;85(3):257-268 [doi: 10.1093/ptj/85.3.257]

131. Altman DG. Practical Statistics for Medical Research. Boca Raton, Florida, United States: CRC press; 1990.

132. McHugh ML. Interrater reliability: the kappa statistic. Biochem Med 2012 Oct 15;22(3):276-282 [doi: 10.11613/bm.2012.031]

133. Linstone HA, Turoff M. Delphi: a brief look backward and forward. Technol Forecast Soc Change 2011 Nov;78(9):1712-1719 [doi: 10.1016/j.techfore.2010.09.011]

134. Duncan EA, Nicol MM, Ager A. Factors that constitute a good cognitive behavioural treatment manual: a Delphi study. Behav Cognit Psychother 2004;32(2):199-213 [doi: 10.1017/s135246580400116x]

135. Boyce WG, Gowland C, Russell D, Goldsmith C, Rosenbaum P, Plews N, et al. Consensus methodology in the development and content validation of a gross motor performance measure. Physiotherapy Canada 1993;45:94-100

136. Loughlin KG, Moore LF. Using Delphi to achieve congruent objectives and activities in a pediatrics department. J Med Educ 1979 Feb;54(2):101-106 [doi: 10.1097/00001888-197902000-00006] [Medline: 762686]

137. McKenna HP. The Delphi technique: a worthwhile research approach for nursing? J Adv Nurs 1994 Jun;19(6):1221-1225 [doi: 10.1111/j.1365-2648.1994.tb01207.x] [Medline: 7930104]

138. Williams PL, Webb C. The Delphi technique: a methodological discussion. J Adv Nurs 1994 Jan;19(1):180-186 [doi: 10.1111/j.1365-2648.1994.tb01066.x] [Medline: 8138622]

139. Bland M. An Introduction to Medical Statistics. Oxford, UK: Oxford University Press; 1995.

140. Lee S, Lee DK. What is the proper way to apply the multiple comparison test? Korean J Anesthesiol 2018 Oct;71(5):353-360 [FREE Full text] [doi: 10.4097/kja.d.18.00242] [Medline: 30157585]

141. McCrum-Gardner E. Which is the correct statistical test to use? Br J Oral Maxillofac Surg 2008 Jan;46(1):38-41 [doi: 10.1016/j.bjoms.2007.09.002] [Medline: 17961892]

142. 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):e34 [FREE Full text] [doi: 10.2196/jmir.6.3.e34] [Medline: 15471760]

143. Johnson JK, Barach PR. Improving pediatric cardiac care with continuous quality improvement methods and tools. In: Barach P, Jacobs J, Lipshultz S, Laussen P, editors. Pediatric and Congenital Cardiac Care. London: Springer; 2015.

144. Trebble TM, Hansi N, Hydes T, Smith MA, Baker M. Process mapping the patient journey: an introduction. BMJ 2010 Aug 13;341:c4078 [doi: 10.1136/bmj.c4078] [Medline: 20709715]

145. Haldeman S, Johnson CD, Chou R, Nordin M, Côté P, Hurwitz EL, et al. The Global Spine Care Initiative: care pathway for people with spine-related concerns. Eur Spine J 2018 Sep;27(Suppl 6):901-914 [doi: 10.1007/s00586-018-5721-y] [Medline: 30151811]

146. El Karim IA, Duncan HF, Cushley S, Nagendrababu V, Kirkevang LL, Kruse C, et al. A protocol for the development of Core Outcome Sets for Endodontic Treatment modalities (COSET): an international consensus process. Trials 2021 Nov 17;22(1):812 [FREE Full text] [doi: 10.1186/s13063-021-05764-x] [Medline: 34789318]

147. 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):1651-1658 [doi: 10.2106/JBJS.L.00589] [Medline: 24048552]

148. Rhee JM, Shamji MF, Erwin WM, Bransford RJ, Yoon ST, Smith JS, et al. Nonoperative management of cervical myelopathy: a systematic review. Spine (Phila Pa 1976) 2013 Oct 15;38(22 Suppl 1):S55-S67 [doi: 10.1097/BRS.0b013e3182a7f41d] [Medline: 23963006]

149. Waheed MA, Hasan S, Tan LA, Bosco A, Reinas R, Ter Wengel PV, et al. Cervical spine pathology and treatment: a global overview. J Spine Surg 2020 Mar;6(1):340-350 [FREE Full text] [doi: 10.21037/jss.2020.01.12] [Medline: 32309671]

150. Dicicco-Bloom B, Crabtree BF. The qualitative research interview. Med Educ 2006 Apr;40(4):314-321 [doi: 10.1111/j.1365-2929.2006.02418.x] [Medline: 16573666]

151. Kiekens A, Dierckx de Casterlé B, Vandamme A. Qualitative systems mapping for complex public health problems: a practical guide. PLoS One 2022 Feb 25;17(2):e0264463 [FREE Full text] [doi: 10.1371/journal.pone.0264463] [Medline: 35213648]

152. WINS White Paper Committee:, Benzil DL, Abosch A, Germano I, Gilmer H, Maraire JN, et al. The future of neurosurgery: a white paper on the recruitment and retention of women in neurosurgery. J Neurosurg 2008 Sep;109(3):378-386 [doi: 10.3171/JNS/2008/109/9/0378] [Medline: 18759565]

153. Lincoln YS, Guba EG. Naturalistic Inquiry. Thousand Oaks, CA: SAGE Publications; 1985.

154. Rowlands J. Interviewee transcript review as a tool to improve data quality and participant confidence in sensitive research. Int J Qual Methods 2021 Dec 16;20:160940692110661 [doi: 10.1177/16094069211066170]

155. Given LM. The SAGE Encyclopedia of Qualitative Research Methods. Thousand Oaks, CA: SAGE Publications; 2008.

156. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101 [doi: 10.1191/1478088706qp063oa]

157. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. Int J Qual Methods 2016 Nov 30;1(2):13-22 [doi: 10.1177/160940690200100202]

158. Antonacci G, Reed JE, Lennox L, Barlow J. The use of process mapping in healthcare quality improvement projects. Health Serv Manage Res 2018 May 30;31(2):74-84 [FREE Full text] [doi: 10.1177/0951484818770411] [Medline: 29707978]

159. DrugTherapeutics Bulletin. An introduction to patient decision aids. BMJ 2013 Jul 23;347:f4147 [doi: 10.1136/bmj.f4147] [Medline: 23881944]

160. Khalifeh H, Molyneaux E, Brauer R, Vigod S, Howard LM. Patient decision aids for antidepressant use in pregnancy: a pilot randomised controlled trial in the UK. BJGP Open 2019 Dec 10;3(4):bjgpopen19X101666 [doi: 10.3399/bjgpopen19x101666]

161. Montori VM, Kunneman M, Brito JP. Shared decision making and improving health care: the answer is not in. JAMA 2017 Aug 15;318(7):617-618 [doi: 10.1001/jama.2017.10168] [Medline: 28810005]

162. Stacey D, Légaré F, Lewis KB. Patient decision aids to engage adults in treatment or screening decisions. JAMA 2017 Aug 15;318(7):657-658 [doi: 10.1001/jama.2017.10289] [Medline: 28810006]

163. Smith SS, Stewart ME, Davies BM, Kotter MR. The prevalence of asymptomatic and symptomatic spinal cord compression on magnetic resonance imaging: a systematic review and meta-analysis. Global Spine J 2021 May 24;11(4):597-607 [FREE Full text] [doi: 10.1177/2192568220934496] [Medline: 32677521]

164. Norris SL, Nichols PJ, Caspersen CJ, Glasgow RE, Engelgau MM, Jack L, et al. The effectiveness of disease and case management for people with diabetes. A systematic review. Am J Prev Med 2002 May;22(4 Suppl):15-38 [doi: 10.1016/s0749-3797(02)00423-3] [Medline: 11985933]

165. Zhu SH, Stretch V, Balabanis M, Rosbrook B, Sadler G, Pierce JP. Telephone counseling for smoking cessation: effects of single-session and multiple-session interventions. J Consult Clin Psychol 1996;64(1):202-211 [doi: 10.1037/0022-006x.64.1.202]

166. Parchman ML, Zeber JE, Palmer RF. Participatory decision making, patient activation, medication adherence, and intermediate clinical outcomes in type 2 diabetes: a STARNet study. Ann Fam Med 2010;8(5):410-417 [FREE Full text] [doi: 10.1370/afm.1161] [Medline: 20843882]

167. Deakin TA, Cade JE, Williams R, Greenwood DC. Structured patient education: the diabetes X-PERT Programme makes a difference. Diabet Med 2006 Sep;23(9):944-954 [FREE Full text] [doi: 10.1111/j.1464-5491.2006.01906.x] [Medline: 16922700]

168. Gøtzsche PC, Johansen HK, Schmidt LM, Burr ML. House dust mite control measures for asthma. Cochrane Database Syst Rev 2004 Oct 18(4):CD001187 [FREE Full text] [doi: 10.1002/14651858.CD001187.pub2] [Medline: 15495009]

169. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA 2002 Nov 20;288(19):2469-2475 [doi: 10.1001/jama.288.19.2469] [Medline: 12435261]

170. Tetreault LA, Kopjar B, Vaccaro A, Yoon ST, Arnold PM, Massicotte EM, et al. A clinical prediction model to determine outcomes in patients with cervical spondylotic myelopathy undergoing surgical treatment: data from the prospective, multi-center AOSpine North America study. J Bone Joint Surg Am 2013 Sep 18;95(18):1659-1666 [doi: 10.2106/JBJS.L.01323] [Medline: 24048553]

171. Tetreault L, Wilson JR, Kotter MR, Nouri A, Côté P, Kopjar B, et al. Predicting the minimum clinically important difference in patients undergoing surgery for the treatment of degenerative cervical myelopathy. Neurosurg Focus 2016 Jun;40(6):E14 [doi: 10.3171/2016.3.focus1665]

172. Moghaddamjou A, Wilson JR, Martin AR, Gebhard H, Fehlings MG. Multidisciplinary approach to degenerative cervical myelopathy. Expert Rev Neurother 2020 Oct 04;20(10):1037-1046 [doi: 10.1080/14737175.2020.1798231] [Medline: 32683993]

173. 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 Jun 30;11(1):e36194 [FREE Full text] [doi: 10.2196/36194] [Medline: 35771617]

174. Santaguida P, Dolovich L, Oliver D, Lamarche L, Gilsing A, Griffith LE, et al. Protocol for a Delphi consensus exercise to identify a core set of criteria for selecting health related outcome measures (HROM) to be used in primary health care. BMC Fam Pract 2018 Sep 04;19(1):152 [FREE Full text] [doi: 10.1186/s12875-018-0831-5] [Medline: 30185172]

175. Delmar C. The excesses of care: a matter of understanding the asymmetry of power. Nurs Philos 2012 Oct;13(4):236-243 [doi: 10.1111/j.1466-769X.2012.00537.x] [Medline: 22950727]

176. Green RA. The Delphi technique in educational research. SAGE Open 2014 Apr 16;4(2):215824401452977 [doi: 10.1177/2158244014529773]

177. Davies B, Kotter M. Lessons from recruitment to an internet-based survey for degenerative cervical myelopathy: comparison of free and fee-based methods. JMIR Res Protoc 2018 Feb 05;7(2):e18 [FREE Full text] [doi: 10.2196/resprot.6567] [Medline: 29402760]

178. Gambatese JA, Behm M, Rajendran S. Design's role in construction accident causality and prevention: perspectives from an expert panel. Safety Sci 2008 Apr;46(4):675-691 [doi: 10.1016/j.ssci.2007.06.010]

179. Clibbens N, Walters S, Baird W. Delphi research: issues raised by a pilot study. Nurse Researcher 2012 Jan 26;19(2):37-44 [doi: 10.7748/nr2012.01.19.2.37.c8907]

180. Sinha IP, Smyth RL, Williamson PR. Using the Delphi technique to determine which outcomes to measure in clinical trials: recommendations for the future based on a systematic review of existing studies. PLoS Med 2011 Jan 25;8(1):e1000393 [FREE Full text] [doi: 10.1371/journal.pmed.1000393] [Medline: 21283604]

181. Niederberger M, Spranger J. Delphi technique in health sciences: a map. Front Public Health 2020 Sep 22;8:457 [FREE Full text] [doi: 10.3389/fpubh.2020.00457] [Medline: 33072683]

182. Tuckett AG. Applying thematic analysis theory to practice: a researcher's experience. Contemp Nurse 2005 Dec 17;19(1-2):75-87 [doi: 10.5172/conu.19.1-2.75] [Medline: 16167437]

183. Saldana J. The Coding Manual for Qualitative Researchers. Thousand Oaks, CA: SAGE Publications; 2009.

Abbreviations

CIS: core information set
DCM: degenerative cervical myelopathy
HCP: health care professional
RECODE-DCM: Research Objectives and Common Data Elements for Degenerative Cervical Myelopathy
SDM: shared decision-making

XSL·FO

RenderX