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Participatory research

a Priority Setting Partnership for chronic musculoskeletal pain in Denmark

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Original Experimental

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Participatory research: a Priority Setting Partnership for chronic musculoskeletal pain in Denmark

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Abstract

Objectives: Patient and stakeholder engagements in research have increasingly gained attention in healthcare and healthcare-related research. A common and rigorous

approach to establish research priorities based on input from people and stakeholders is the James Lind Alliance Priority Setting Partnership (JLA-PSP). The aim of this study was to establish research priorities for chronic musculoskeletal (MSK) pain by engaging with people living with chronic MSK pain, relatives to people living with chronic MSK pain, healthcare professionals (HCP), and researchers working with chronic MSK pain.

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Methods: This JLA-PSP included a nation-wide survey in Denmark, an interim prioritisation, and an online consensus building workshop. The information gained from this was the basis for developing the final list of specific research priorities within chronic MSK pain.

Results: In the initial survey, 1010 respondents (91% people living with chronic MSK pain/relatives, 9% HCPs/researchers) submitted 3121 potential questions. These were summarised into 19 main themes and 36 sub-themes. In the interim prioritisation exercise, 51% people living with pain/relatives and 49% HCPs/researchers reduced the list to 33 research questions prior to the final priority setting workshop. 23 participants attended the online workshop (12 people/relatives, 10 HCPs, and 1 researcher) who reached consensus for the most important research priorities after two rounds of discussion of each question.

Conclusions: This study identified several specific research questions generated by people living with chronic MSK pain, relatives, HCPs, and researchers. The stakeholders proposed prioritization of the healthcare system's ability to support patients, focus on developing coherent pathways between sectors and education for both patients and HCP. These research questions can form the basis for future studies, funders, and be used to align research with end-users' priorities.

Keywords: chronic musculoskeletal pain; patient and public involvement; research priorities.

Background

According to the World Health Organization (WHO), between 20 and 33% of the world population lives with a painful musculoskeletal (MSK) condition [1]. As the costs due to MSK pain correspond to almost 2% of the gross domestic products of European countries, MSK pain poses a challenge for healthcare systems across the world [2, 3]. People with chronic MSK pain have a high use of healthcare services, reduced work ability, loss of productivity, and lower quality of life [4, 5]. In Denmark, it is estimated that 1.2 million Danish citizens (approximately 20% of the Danish population) experience chronic MSK pain some time during life [6]. One in every four long-term sick leaves and 14% of all early retirements are caused by chronic MSK pain [6, 7]. Many people with chronic MSK pain have widespread complaints and deal with concurrent insomnia, anxiety, depression, and loneliness [8–11]. This underlines that chronic MSK pain is a multifaceted problem and affects all aspects of life, limiting activities of daily living and work ability while increasing medical expenditure.

To identify the individually lived experiences with a chronic pain condition, there is a need to include their perspectives in the research agenda. The emerging concept of early and continuous involvement of people living with different conditions in research is internationally recognized as a priority [12, 13]. A recent example is the International Association for the Study of Pain (IASP) establishing the Global Alliance of Partners for Pain Advocacy (GAPPA). Previous research has shown that the traditional research does not always align with the needs and preferences of people living with a pain condition and healthcare professionals treating the condition (HCPs) [14–16].

To accommodate the lack of end-user involvement, the James Lind Alliance (JLA) was established to create a framework for Priority Setting Partnerships (PSPs) which provides a platform where end-users and researchers can work together on shaping an agenda for future research within a certain field. In the PSP framework, surveys and workshops are used to capture questions from end-users and to define research priorities that can address future research on replying to unanswered so-called uncertainties [17]. Research priorities can vary across social groups and geographically between and within a country, highlighting the need for national initiatives to uncover uncertainties [18]. Several studies have investigated research priorities within MSK pain either using other approaches [19–21] or in specific MSK conditions such as knee arthroplasty, spinal cord injuries, fibromyalgia [22–24], but no studies have investigated the research priorities in relation to a broader scope of chronic MSK pain within a national Danish context using the JLA-PSP approach. The objective of this study was to establish a list of top-research priorities for chronic MSK pain to formulate specific research questions using the JLA-PSP framework.

Methods

Study design

This study is reported according to the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) short form checklist [25]. The study was published prior to peer-review on the preprint server MedRxiv (DOI: <https://doi.org/10.1101/2021.12.17.21267948>). The study was conducted using a modified version of the JLA framework for conducting PSPs. It differed from the traditional approach by not using a specific JLA advisor and because the aim was to develop specific research questions instead of producing a top-10 list. The methodology aimed at gathering inputs from several key stakeholders involved in the management of daily living with chronic MSK pain in Denmark, including people with lived experience, relatives, HCPs,

and researchers. The study consisted of 4 phases, including: initial online survey, survey analysis, interim prioritisation exercise, and an online workshop. Additionally, the project group included three experts with previous experience conducting PSPs within chronic pain (KB, JS, and PP). All data were collected and managed through REDcap (Research Electronic Data Capture) hosted at Aalborg University [26, 27]. REDcap is a secure, web-based software platform designed to support data capture for research studies.

Project organisation

We established both a project group (PG) and a steering group (SG). The PG was in charge of developing the protocol, managing data, and publishing the results. The PG was restricted to researchers and research-HCPs. Additionally, we established both an SG restricted to people with lived experience and patient organisations and an SG restricted to HCPs, chaired by KDL. The SGs ensured equal input to all steps in the process both from people living with chronic MSK pain and HCPs. The SG included people with lived experience and representatives from three different patient organisations (the Association for Chronic Pain Patients, the Danish Fibromyalgia & Pain Association, and the Danish Rheumatism Association), researchers and HCPs working within the field of chronic MSK pain and at least one of the authors from the Danish national clinical guidelines relating to pain. The individually assigned tasks for the PG and SG can be seen in Table 1.

Participants

For all steps of the PSP process, we included both people living with chronic MSK pain, relatives to people living with chronic MSK pain, HCPs, and researchers who were working with people living with chronic MSK pain. People living with chronic MSK pain were self-assessed based on the new definitions from the ICD-11 codes and the classification of chronic primary pain:

Pain in one (or more anatomical regions) that persists or recurs for more than 3 months and is associated with significantly emotional distress or functional disability (interference with activities of daily life and participation in social roles) and that cannot be better accounted for by another chronic pain condition [28, 29]

Table 1: Definitions of project and steering groups.

What	Who	Role and responsibilities
Project group	Researchers and research-clinicians (n=14)	Protocol preparation, study management, data management and analysis, publication, knowledge translation.
Steering groups	People with CMP, their relatives, relevant patient-organizations, HCPs, and researchers. (n=19)	Providing inputs to protocol, survey, categorization, interim ranking, workshop, final formulation of research questions and knowledge mobilisation

HCP, health-care practitioners; CMP, chronic musculoskeletal pain.

Relatives and people living with chronic MSK pain fulfilling the above were included. Health-care professionals were considered eligible for participation if they presently worked full-time with treating people living with chronic MSK pain. Also, only authorised HCPs including medical doctors, nurses, chiropractors, physiotherapists, occupational therapists, psychologists, or social workers were eligible to participate. Researchers were included if they had three years or more of experience within the field of chronic MSK pain and at least one first authored or senior authored paper within the field. People with chronic secondary pain (e.g. sequelae from chemotherapy, surgical procedures, or visceral pain) were not eligible for participation.

Phase 1: national online survey including multiple stakeholders

To collect evidence of uncertainties in relation to chronic MSK pain in Denmark, we created a respondent-tailored online survey for people with lived experience, relatives, HCPs, and researchers. The survey was distributed using a multimodal recruitment strategy through personal networks (e.g. email and mouth-to-mouth), patient organisations (the Association for Chronic Pain Patients, the Danish Fibromyalgia & Pain Association, and the Danish Rheumatism Association), and social media (targeted advertisement through Facebook), thereby covering all geographical areas of Denmark. The survey was developed within both SGs and in an iterative collaboration with people representing ethnical minorities in Denmark and linguists to ensure that the survey would be easily understandable, independent of reading capabilities. The survey included demographic questions, an option (i.e. “Which questions do you want future research to answer”) to capture the priorities from the respondents (a maximum of five questions were given) and finally, an invitation to participate in future steps of the process and/or in future projects in relation to the chronic MSK pain. None of the respondents were reimbursed for their participation.

Phase 2: analysis of survey

The analysis of the survey data followed the step-by-step guidebook developed by JLA [17]. Initially, data was imported into NVivo 12 for qualitative data analysis. Secondly, questions were sorted through naive reading and excluded if the questions were out-of-scope, unidentifiable, lacked information, or too individualised. Excluded questions were reviewed by at least two SG members, one person with lived experience and one representative from a patient organisation to ensure that the questions were truly out-of-scope (e.g. irrelevant to this area, not understandable). Thirdly, the remaining eligible questions were categorised in NVivo and sorted into initial themes, main themes, and underlying sub-themes by one author (KDL). Transcriptions of raw data was cross-checked by two representatives with a scientific background (JBL and MSR) and two authors with a patient-background (LBM and JO). Themes with <5 individual uncertainties were excluded by the concept of saturation [30]. Fourthly, indicative questions were formulated as true to the data as possible and rephrased into one theme when several questions fitted into one. The final list of indicative research questions was co-developed with both SGs to ensure relevance for all stakeholders.

Phase 3: interim prioritisation

To reduce the final list of indicative research questions prior to the priority-setting workshop, we conducted an online interim prioritisation exercise. Participants from phase 1, who agreed to participate in further steps, were invited to take part in the interim prioritisation exercise. Participants were asked to rank the importance of each research question on a 5-point Likert scale from 1 to 5; with 1 = not at all important, 2 = low importance, 3 = Neutral, 4 = Important, to 5 = very important. The scores for all participants were merged and thus illustrated which research questions were deemed most important by the participants. These were included in the priority-setting workshop.

Phase 4: priority-setting workshop

A final list of the top research priorities was established by inviting people, relatives, and HCPs to participate in a 3-h online workshop. Participants from the original survey in step 1, were asked to participate again. They were included on a first come, first served basis. The workshop used a nominal group technique approach with a combination of small and large group exercises, which were facilitated by two individuals from the project group (KDL and MSH) and an external facilitator, all with prior experience in conducting workshops. To establish the final list, we used a consensus approach and a final voting to choose the top priorities. All participants were split into three groups with representation of both persons with lived experience and HCP in every group. All questions were discussed and reviewed, and the least important research priorities determined by consensus were removed first. The following step focused on sorting and agreeing on the most important research priorities within the three groups before presenting for the entire group. Finally, all participants were asked to choose the two most important research priorities in their view which then constituted the final list of priorities.

Results

Phase 1: national survey including multiple stakeholders

The survey was viewed by 1017 participants and completed by 1010 (89.5% people with lived experience, 8.8% HCPs, and 1.7% relatives) who suggested 3121 individual research questions. 64% of the HCPs worked in the primary sector, 35% worked in the secondary sector, and 37% worked in the tertiary sector. 675 respondents agreed to participate in later steps of the process (66%). Participants' characteristics for phase 1, 3, and 4 can be seen in Table 2.

Phase 2: analysis of survey

127 uncertainties (4.24%) were excluded for being out-of-scope, unidentifiable, or missing information. The remaining 2994 uncertainties were then transformed into

Table 2: Participant characteristics.

	No. (%) of participants		
	Phase 1: Survey n=1,010 (%)	Phase 2: Interim prioritisation n=97 (%)	Phase 3: Workshop n=23 (%)
Participants			
Person living with chronic MSK pain	904 (89.50)	45 (46.39)	11 (47.82)
Relative to a person living with chronic MSK pain	16 (1.58)	4 (4.12)	1 (4.34)
Medical Doctor	15 (1.48)	13 (13.40)	2 (8.69)
Physiotherapist	22 (2.21)	15 (15.46)	6 (26.08)
Other HCPs (Psychologist, Nurse, Chiropractor, Social worker, Researcher)	53 (5.22)	20 (20.61)	6 (26.04)
Sex			
Female	939 (92.97)	75 (77.3)	21 (91.3)
Male	71 (7.03)	22 (22.7)	2 (8.7)
Age			
18–30	52 (5.1)	3 (3.0)	1 (4.3)
31–40	106 (10.4)	44 (47.4)	3 (13.2)
41–50	283 (27.9)	12 (12.4)	12 (52.2)
51–60	366 (36.0)	25 (25.7)	6 (26)
61–70	168 (16.5)	12 (12.4)	1 (4.3)
71–80	39 (3.8)	0	0
80+	2 (0.2)	0	0
Region			
Region of Northern Jutland	130 (12.8)	27 (27.8)	6 (26)
Region Central Denmark	227 (22.3)	25 (25.7)	4 (17.3)
Region Southern Denmark	189 (18.6)	18 (18.5)	3 (13.2)
Region Zealand	206 (20.3)	12 (12.4)	6 (26)
Region Capital	264 (26)	15 (15.4)	4 (17.3)
Ethnicity			
Danish	979 (96.4)	94 (97)	22 (95.7)
Immigrant, non-western	7 (0.7)	0	0
Immigrant, western	15 (1.5)	1 (1)	1 (4.3)
Descendant, non-western	2 (0.2)	1 (1)	0
Descendant, western	1 (0.1)	1 (1)	0
Do not want to state	12 (1.2)	0	0

50 initial themes (see Table 3) and then condensed into 19 main themes and 36 sub-themes which were formulated into research questions (see Table 4).

Phase 3: interim prioritisation

Participants from phase 1 and all members from both steering groups (n=19) were invited to participate in the

Table 3: Initial themes.

Initial themes
Biomedical approach, Biopsychosocial approach, Care-pathway, Characteristics, Classification, Cognition, Coping, Cross-sectional Management, Diagnosis, Education (HCPs), Education (People living with chronic MSK pain), Environment, Equal treatment options, Ethnicity, Fatigue, Financial support, Gender differences, Genetics, Implementation, Insurance, Job centre, Measurement, Mechanism, Municipal management, Needs and preferences, Nudging, Nursing, Nutrition, Pacing, Pain Fluctuations, Pain Spreading, Physical limitations, Prevention, Prognosis, Psychological, Public Awareness, Quality of Life, Relatives, Self-management, Sequelae, Sex, Shared decision-making, Sleep, Stigma, Stress, Therapeutic alliance, Treatment, Understanding of pain, Vitamins, Work.

interim prioritisation exercise and 97 people (45 people living with chronic MSK pain, 4 relatives, 34 HCPs, and 14 researchers) completed the exercise (24% completion rate). Based on the interim prioritisation exercise, the seven research questions with the lowest scores were excluded. This left us with 33 research questions, which were deemed an appropriate number of questions to handle at the priority-setting workshop (see Appendix 1).

Phase 4: priority-setting workshop

Twenty-three participants (including 11 people living with chronic MSK pain, 1 relative, 10 HCPs, and 1 researcher) participated in the online workshop to establish the most important research priorities in relation to chronic MSK pain. The final voting for the most important research questions can be seen in Table 5. After initial discussions in the group phase, all participants discussed and voted for the most important research questions related to chronic MSK pain. This prioritized list of research questions can be seen in Table 5. Full list of research questions for the workshop can be found in Appendix 2.

Discussion

Via an iterative process as a collaboration between people living with chronic MSK pain, relatives, HCPs, and researchers, we developed a set of research priorities for research areas of interest within the domain of chronic MSK pain in Denmark. Our process demonstrated that future research should prioritise investigation of how the healthcare system can offer support and better pathways between sectors, thereby leading to a

coherent collaboration between patient, relatives, municipality, and various HCPs. Increased focus should also be given on education of patients, relatives, and HCPs to increase the general knowledge across all stakeholders involved in the management of chronic MSK pain. Overall, the PSP study has highlighted which research questions that the stakeholders within chronic MSK pain would like to see investigated.

Comparisons with previous Priority Setting Partnerships

The scope of our PSP was intentionally broad and included chronic MSK pain and not a specific diagnosis as e.g. hip or knee osteoarthritis. Our choice was based on current understanding that many people suffer from MSK pain in multiple sites where the pain and impact of pain are the most important aspects, and not the specific pathology. Widespread symptoms in people with chronic MSK pain is not uncommonly reported and might be influenced by psychological and social factors [8, 9]. This highlights that chronic MSK pain is a multifactorial condition. Despite not being related to a specific condition, our PSP identified similar research priorities as several other PSPs which identified improvements of treatments for pain and function (e.g. knee arthroplasty) [22, 31–35], improving healthcare organisation (e.g. paediatric chronic pain) [22, 33, 34], improving the knowledge of living with a painful condition (e.g. people with fragile fractures in lower limb and pelvis) [31, 33, 34], improving the accuracy of diagnosis and referral (e.g. shoulder surgery) [22, 36, 37] and improving quality of life and public awareness, and avoid stigmatisation as seen in other conditions such as depression, dementia, diabetes, and cancer [38–41]. As a contrast to previous PSPs, our priorities included a strong focus on areas outside typical treatments focusing on improving pain and function. We identified priority areas that included an improved societal understanding and organisation of healthcare for people living with chronic MSK pain. The difference in priorities compared with previous PSPs may reflect a time-based change in the perception of chronic MSK pain. Previously considered a primarily biomedical condition, chronic MSK pain is now considered a condition developed from a maintained by multiple factors, which may co-exist with other conditions [42–44]. This highlights that to target these research priorities, it is essential to collaborate and form partnerships across institutions and sectors and involve researchers outside the healthcare profession.

Table 4: Thematic analysis of survey.

Main theme	Sub-theme	Indicative question [uncertainty]	No. uncertainties	Summary
Care-pathway	Retention	How can the healthcare system avoid 'losing' people living with chronic MSK pain dealing with CMP, and keep them in the 'loop' independent of income and geography?	41 People living with chronic MSK pain	This question mainly focuses on how people living with chronic MSK pain that deal with severe disability, who often experience that they have been forgotten by the healthcare system, and therefore needs research on how the system can better retain people living with chronic MSK pain who needs to be retained. N/A
Care-pathway	Referral	How can we ensure that people living with chronic MSK pain receive the appropriate referrals, quicker?	66 People living with chronic MSK pain	N/A
Care-pathway	Flow	How can current care-pathways be improved to ensure a better more fluid organisation and thereby create a better flow in care-pathway with shorter waiting-times?	92 All groups	This question derives from uncertainties relating to care-pathways that is often considered as inefficient and therefore associated with long periods of uncertainty.
Care-pathway	Cross-professional	How can specialised pain clinics support people living with chronic MSK pain living with CMP and can it be a better individualised alternative to usual care-pathways?	108 All groups	This question evolves around the need for improved care-pathways and as an alternative to usual care, all groups want to know how cross-professional management, for example using specialized pain clinics, can be used as potential 'better' care pathway for people living with chronic MSK pain with CMP
Care-pathway	Coordinator	What would be the effect of having support-staff to coordinate rehabilitation of people living with chronic MSK pain living with CMP?	29 People living with chronic MSK pain	People living with chronic MSK pain with CMP who lacks the greater overview over the different offers that exist within the healthcare system, wants to know how personalised help from a coordinator (i.e. staff) can improve their experience with their care-pathway. N/A
Complications	Cognition	How does CMP affect the patient in pain and how can we decrease the impact that pain has on cognition, concentration and memory?	28 People living with chronic MSK pain	N/A
Complications	Symptoms	How can we explain the symptoms that people living with chronic MSK pain with CMP experience and how can we explain the changes (e.g. fluctuations, spreading) that occur in people living with chronic MSK pain with CMP?	31 People living with chronic MSK pain	N/A
Complications	Fatigue	How common is fatigue in people living with chronic MSK pain with CMP, why do people living with chronic MSK pain feel fatigued (mechanism) and how do we decrease the levels of fatigue in people living with chronic MSK pain with CMP (treatment)?	45 People living with chronic MSK pain	N/A
Cross-sectional Management	Collaboration	Which effect does cross-sectional management of people living with chronic MSK pain with CMP have compared to usual care and if more effective, how do we improve current cross-sectional management?	77 All groups	Based on the uncertainties from the survey all groups question the inefficient or in some cases absent cross-sectional management and therefore, asks how cross-sectional communication and general management can be improved to further improve the life of people living with chronic MSK pain with CMP.

Table 4: (continued)

Main theme	Sub-theme	Indicative question [uncertainty]	No. uncertainties	Summary
Diagnosis	Diagnostic uncertainty	How does diagnostic uncertainty impact people living with chronic MSK pain with CMP and how can (earlier) diagnostic clarity improve acceptance of life circumstances?	55 People living with chronic MSK pain	This theme revolves around how we can improve the way clinicians diagnose CMP and how this can be performed faster, more accurate and how we can identify those people living with chronic MSK pain predisposed for CMP.
Diagnosis	Fast-track	How can we reduce the time to diagnosis and minimise errors in diagnosing people living with chronic MSK pain with CMP?	27 All groups	Lastly, people living with chronic MSK pain want research that uncover the impact of diagnostic uncertainty and how this uncertainty can be dealt with the help of the healthcare system.
Diagnosis	Test	Why is it so difficult to diagnose CMP and how can we improve test to diagnose CMP more efficiently?	40 People living with chronic MSK pain	
Diagnosis	Early identification	How can we identify/trace those people living with chronic MSK pain predisposed for CMP or diagnose people living with chronic MSK pain earlier (i.e. teenage years)?	31 People living with chronic MSK pain	
Education (People living with chronic MSK pain)	Empowerment	How can patient education be improved in order to make patient more knowledgeable in their own condition and thereby take more ownership and self-manage?	45 All groups	All groups gave survey responses which led to the questions, (1) what do patient educational packages need to entail and how should they be delivered and (2) how can we improve the education the people living with chronic MSK pain receive and how can it empower the people living with chronic MSK pain' self-management.
Education (People living with chronic MSK pain)	Delivery	What do people living with chronic MSK pain living with CMP need to know and how should patient education be delivered?	21 All groups	This theme asks the questions (1) what do clinicians need to know about CMP and (2) how can the knowledge of HCPs be increase in order to improve general care of people living with chronic MSK pain with CMP.
Education (HCP)	Knowledge	What do clinicians need to know and how can we improve the general level of knowledge of CMP ensure better management of these people living with chronic MSK pain?	180 All groups	This theme asks how (1) CMP develops in persons, (2) who's at risk for developing it and which risk factors and (3) how does common treatment options work.
Mechanism	Mechanism and risk factors	What is the mechanism and which risk factors (e.g. other illness) are associated with developing CMP?	560 All groups	
Mechanism	Gender differences	Which role does gender plays in developing CMP and how can this knowledge guide management?	12 People living with chronic MSK pain	
Mechanism	Treatment	What is the mechanism of action of the most common treatments and how can this knowledge improve the management of CMP?	315 All groups	
Mechanism	Genetics	What is the role of genetics in both developing pain and inherit pain?	45 All groups	This question revolves around people living with chronic MSK pain need to understand the role of genetics (i.e. epigenetics) and how genetics can be used to treat and understand pain, but also if CMP can be inherited to the next generation.

Table 4: (continued)

Main theme	Sub-theme	Indicative question [uncertainty]	No. uncertainties	Summary
Municipal Management	N/A	How can we ensure that patient living with CMP receives the same support in the municipalities to avoid stigmatisation and dissatisfaction?	51 People living with chronic MSK pain	This question revolves around how some people living with chronic MSK pain experience poor management when entering the municipalities and therefore, wants future research to focus on how to improve the management of people living with chronic MSK pain with CMP in the municipalities. N/A
Municipal Management	Responsibility	What is the role and responsibilities of the municipalities in managing people living with chronic MSK pain with CMP and how can we improve the management that people living with chronic MSK pain receive in the municipalities?	21 All groups	N/A
Nutrition	Role	Which role does nutrition (including vitamins) have in the development and persistence of CMP?	7 People living with chronic MSK pain	N/A
Nutrition	Effect	What is the effect of various diets, foods and supplements on CMP?	38 All groups	N/A
Prognosis	N/A	Which role does increases in pain play in the prognosis of pain, and how can we collect and disseminate knowledge on the prognosis to people living with chronic MSK pain living with CMP and what can people living with chronic MSK pain expect their lives to look like?	78 People living with chronic MSK pain	People living with chronic MSK pain want future research to focus on the knowledge of prognosis. More specific they need research to focus on how the action of today's impact their future daily life and if their pain condition can be improved or even completely resolve.
Psycho-social	Influence	What is the psycho-social consequences of dealing with CMP and what is the association between psycho-social factors and developing CMP?	18 People living with chronic MSK pain	This theme covers the need for future research to focus on the psycho-social impact on the life of people living with chronic MSK pain living with CMP. Derived from the uncertainties the questions that needs answered is (1) how psychological conditions influence CMP, (2) what impact does CMP have on both your psychological and social state and (3) Can interventions that specifically targets psychological and social aspects improve the lives of people living with chronic MSK pain with CMP. N/A
Psycho-social	Management	What is to role of early psycho-social intervention in reducing pain and the impact of CMP on daily living?	52 All groups	N/A
Quality of Life	N/A	How does CMP impact QoL and how can different management strategies improve daily living?	38 All groups	N/A
Relatives	Inclusion	How can we include relatives more into the situation of living with pain – how can we educate them and make them comfortable with their role living with a person with CMP?	10 People living with chronic MSK pain and relatives	N/A
Sex	Dysfunction	How can the sexual life of people living with chronic MSK pain living with CMP be improved?	8 People living with chronic MSK pain	N/A
Sleep	Impact	Which consequences do limited sleep have on people living with chronic MSK pain living with CMP?	16 People living with chronic MSK pain	With the help of people living with chronic MSK pain this theme asks, (1) how does limited sleep and/or poor sleep quality impact people living with chronic MSK pain living the

Table 4: (continued)

Main theme	Sub-theme	Indicative question [uncertainty]	No. uncertainties	Summary
Sleep	Improving	What can we do to improve sleep quality in people living with chronic MSK pain living with CMP both using medical treatments and using natural treatments?	68 People living with chronic MSK pain	CMP and (2) how can limited sleep and/or poor sleep quality be improved with intervention?
Stigmatisation	Management	How severe is stigmatisation in current care and how does it influence the management of people living with chronic MSK pain with CMP?	12 People living with chronic MSK pain	People living with chronic MSK pain want to uncover the stigmatisation in clinical practice and how this influence decisions, treatment and the general management of clinicians throughout the care pathway in regard to people living with chronic MSK pain with CMP.
Stigmatisation	Diagnosis	How can increase awareness of the diagnosis as an equal diagnosis to other more 'accepted' conditions in order to reduce the misbelief that people living with chronic MSK pain with CMP often experience from the healthcare system?	78 People living with chronic MSK pain	Patient want future research to focus on the need for greater levels of awareness and acceptance of CMP within the healthcare system, so that the people living with chronic MSK pain don't feel stigmatised when dealing with the healthcare system.
Stigmatisation	Public Awareness	How can we improve the knowledge of CMP in the public and how can increases public knowledge help people living with chronic MSK pain live a better life with CMP?	34 People living with chronic MSK pain	From the questions given be people living with chronic MSK pain this question revolves around the need to further increase the public awareness and knowledge in regards of CMP with the aim of reducing stigmatisation.
Treatment	Effectiveness	What is the most effective treatment option for people living with chronic MSK pain with CMP and how can the best treatment option be identified, individualised and delivered?	903 All groups	This question builds on the majority of responses from all groups and focusses on the need for developing better treatments or determining the most effective treatment for treating people living with chronic MSK pain with CMP. Furthermore, it revolves around how we can improve how we use existing treatments.
Treatment	Cost	What is the most cost-effective treatment to people living with chronic MSK pain with CMP and how can this knowledge be implemented into clinical practice?	37 HCPs	
Treatment	Equality	How can we ensure that all people living with chronic MSK pain across age, population, ethnicity, health literacy and more will be offered the same treatment options?	45 All groups	Based on responses from both groups, this theme focusses on how we can ensure that treatments will be delivered to all people living with chronic MSK pain equally despite differences in demographics and more.
Work	Retention	How do you keep people living with chronic MSK pain living with CMP to continue working full time or part time and how can we make it easier to deal with work while living with pain?	38 People living with chronic MSK pain	N/A

Table 5: Final end-user generated research priorities for chronic musculoskeletal pain.

Final prioritisation of research questions	Votes (n)
How can specialised pain clinics support people living with chronic MSK pain compared to usual care-pathways?	8
How can we minimise errors in diagnosing people living with chronic MSK pain?	7
How can patient education be improved in order to make patient more knowledgeable in their own condition?	6
What is the most effective treatment option(s) for people living with chronic MSK pain?	4
How can we improve the general level of knowledge chronic MSK pain for clinicians to ensure better management of these people living with chronic MSK pain?	3
How can current care-pathways be improved to ensure a more coherent organisation?	3
How can we ensure that people living with chronic MSK pain receives the same support in the municipalities to avoid stigmatisation and dissatisfaction?	1
What is the mechanism and which risk factors (e.g. other illness) are associated with developing chronic MSK pain?	1
How can we improve the management that people living with chronic MSK pain receive in the municipalities?	1
What is the most cost-effective treatment to people living with chronic MSK pain?	1

Participatory research

Engaging people with lived experience has been endorsed by multiple organisations, including the WHO and IASP, and is seen as a crucial step in solving complex problems within society [45]. Enabling the participation of relevant stakeholders in research provides a deeper understanding of real-life problems and facilitates better implementation of research findings [46, 47]. Additionally, co-creation of research helps mitigate research-waste while guiding decision-makers in changing policies within the health-care system [48]. This study was an example of participatory research, which was co-created with relevant stakeholders to chronic MSK pain. While this approach has multiple advantages, there is still no consensus on the appropriate way to utilise and interpret findings from PSPs into real-life settings. Thus, our results should not be seen as a definitive list of research questions, but as a guide to research areas that reflect the problems faced by people living with chronic MSK pain as well as stakeholders.

Limitations

To capture a broad large sample and limit regional differences, we used an online survey where all who fulfilled the

criteria could respond to the survey. Ultimately, we ended up with a strong overrepresentation of female (93%), the majority were persons living with chronic MSK pain (90%), Danish (97%), and had been living with chronic MSK pain for more than 10 years (~70% of people living with chronic MSK pain). It is unknown if this sample represents the broader population or if these individuals may have certain preferences and priorities. Despite attempts to engage participants with different ethnical backgrounds, we failed to recruit a substantial proportion of participants with other ethnicities than Danish. Minorities often are overlooked in policy making [49–52], and specific efforts are needed to engage these groups in future validation work of this PSP. The lack of descriptors in this study, further limits the study and hampers the identification of the sample. Future studies should collect more information on the respondents included to ensure better representativeness in the general population.

Future implications

This study highlights the uncertainties based on the different stakeholders within musculoskeletal pain. It is well-established that the journey from research to practice is a long and complicated road, that usually takes years to implement [53]. It is, therefore, plausible that some of the uncertainties, might not be a “true” uncertainty, where the evidence is lacking in the specific area. Therefore, it is needed to compare the established priorities from this study, with the quality of the existing research, as seen in similar initiatives [54]. The JLA-PSP approach recommends surveys for collecting research questions. This initial survey lays the foundation for the entire PSP. It might be argued that other approaches may be used to complement this approach as the lived experience of chronic MSK pain might be better understood using phenomenological approaches. Such an approach would provide unique insights into the perspectives of how people perceive their own life experiences with a certain condition, and how knowledge is gained from these experiences [55]. Future studies could consider collecting research questions using qualitative methods such as interpretive phenomenological interviews or attempting to cross-validate the findings from this study using such methods.

Due to COVID-19, we were unable to host a physical workshop as recommended by the JLA [17]. Therefore, we conducted an online workshop through Teams. It is unclear what effect such an approach may have. The evidence regarding the comparison between online and physical workshops is scarce and needs to be further investigated in future studies. Our experience with online workshops were

predominately good, and it allowed people to participate without challenges with transportation, needing to go outside of your home, and limiting time requirements for busy participants. Furthermore, this medium made it easier and safer for more vulnerable participants to feel comfortable. Future research is needed to understand if these online workshops may be a new tool to engage groups which have earlier been underrepresented in PSPs.

Conclusions

While our knowledge on the complexity of the lived experience with chronic MSK pain has increased during the past decades, there are still several unanswered questions. Findings from this PSP can guide researchers and funders to prioritise specific research areas within chronic MSK pain, thereby potentially leading to important improvements within the management of chronic MSK pain. Using the JLA-PSP method and engaging stakeholders in all aspects of the study, we were able to retrieve a list of research priorities from people living with MSK pain, relatives, and healthcare practitioners working with people with chronic MSK pain. To be able to target these research priorities, cross-sectoral collaboration, partnership between stakeholders, and willingness to engage in establishing coherent pathways are required. Our research group has initiated activities to uncover some of these research questions, and we hope that other institutions will also engage in stakeholder driven research activities in future.

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Author contributions: All authors made significant contributions to the design, interpretation, approval of data analysis and manuscript writing. KDL, JBL and MSR

created all surveys in REDCap. KDL and MH acted as facilitators in the workshop. KDL analysed the data. All authors have approved the final version of the manuscript.

Competing interests: All authors state no conflict of interest.

Informed consent: Informed consent was collected to ensure that participants accepted that we were able to contact them for later stages or project and that data from this study were stored on a secure fileshare.

Ethical approval: The study was exempt from a full ethical approval by the The North Denmark Region Committee on Health Research Ethics due to the design of the study.

Appendix 1: Least important research questions

Excluded research questions based on interim prioritisation

- What role does gender plays in developing pain and how can this knowledge guide management?
 - What would be the effect of having support-staff to coordinate rehabilitation of people living with chronic MSK pain?
 - What is the role of genetics in both developing pain and inheriting pain?
 - How can the sexual life of people living with chronic MSK pain be improved?
 - What role does nutrition (including vitamins) have in the development and persistence of chronic MSK pain?
 - What is the effect of various diets, foods, and supplements on chronic MSK pain?
 - What role does increases in pain play in the prognosis of pain, and how can we collect and disseminate knowledge on the prognosis to people living with chronic MSK pain and what can they expect their lives to look like?
-

Appendix 2: Full list of research questions for the workshop

Research questions

- What effect does cross-sectoral handling of people living with chronic MSK pain have, is it more efficient than ordinary handling and can we then optimize the cross-sectoral handling?
- How can we reduce the time before getting a diagnosis while minimizing diagnostic errors?
- How can patient education be improved so that people living with chronic MSK pain become better at dealing with their own pain and gaining more knowledge about their own condition?
- What is the most effective treatment for people living with chronic MSK pain and how can this treatment be identified, individualized, and delivered in the best possible way?
- What do clinicians need to know about chronic MSK pain and how can we improve the overall level of knowledge?

(continued)

Research questions

How can current patient processes be improved so that we create a more fluid process with shorter waiting times?

How can we ensure that people living with chronic MSK pain for a uniform treatment (municipal) and avoid stigma?

What is the reason for developing chronic MSK pain and what risk factors exist for the development of chronic MSK pain?

What role does your municipal management play in the treatment of people living with chronic MSK pain and how can we improve this management?

What is the most cost-effective treatment for people living with chronic MSK pain and how can this knowledge be implemented in practice?

How can we more quickly identify the people who are predisposed to chronic MSK pain?

How to keep people living with chronic MSK pain at work and how can we make it easier for people living with chronic MSK pain to work?

How can we reduce or prevent fatigue in people living with chronic MSK pain?

How can specialized pain clinics help people living with chronic MSK pain and is it a better alternative to regular management?

How can the healthcare system avoid losing people living with chronic MSK pain living and instead retain those who need it, regardless of income and geography?

How do we ensure that people living with chronic MSK pain receive the right referral, faster?

How can current care pathways be improved so that we create a more fluid process with shorter waiting times?

How can specialized pain clinics help people living with chronic MSK pain and is it a better alternative to regular management?

How can we improve diagnostic methods to provide a diagnosis more quickly and accurately?

What do people living with chronic MSK pain need to know about their condition and how should this knowledge be delivered?

What is the mechanism for developing chronic MSK pain and what risk factors exist for the development of chronic MSK pain?

How do respective treatments work and how can we use this knowledge to improve the treatment of chronic MSK pain?

What role does your municipal management play in the treatment of people living with chronic MSK pain and how can we improve this management?

What are the psychosocial consequences of living with chronic MSK pain and what role do psychosocial factors (e.g. anxiety, depression) play in developing chronic MSK pain?

How can we include relatives more and how can we educate them for more security?

What are the consequences of restricting sleep in people living with chronic MSK pain?

How can we improve sleep quality in people living with chronic MSK pain?

How can we improve knowledge about chronic MSK pain in the public and how can this knowledge affect the lives of people living with chronic MSK pain?

How can we ensure that all people living with chronic MSK pain, regardless of background, are offered the same treatment and thereby create a more equal healthcare system?

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