

**The Arthritis Research UK
Musculoskeletal Health Questionnaire**

*Developing and piloting a generic
patient reported outcome measure
for us across musculoskeletal care pathways*



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Background

Painful musculoskeletal conditions are a leading cause of lost quality of life, work absence, and health and social care costs. Each year, the NHS in England spends over £5bn supporting and treating people living with these conditions. An ageing population, combined with rising levels of obesity and physical inactivity, is likely to dramatically increase the number of people whose lives are affected. As health services globally strive to achieve more with less, the relentless quest for better value demands that outcomes are measured, reported and improved at every opportunity.

The health impact of painful musculoskeletal conditions, such as arthritis and back pain, cannot be summarised with biomarkers or imaging. Patient reported outcome measures (PROMs), however, are well suited to this purpose. In England, Oxford Hip and Knee scores are routinely collected before and after joint replacement surgery and the data made available for academic, clinical and business analysis.

However the majority of people receiving care for musculoskeletal conditions do not need surgical treatment. Instead, large numbers of people with a wide range of musculoskeletal problems attend their local GP surgery or see community physiotherapy for their condition. Others will use outpatient services in secondary care, such as rheumatology and pain medicine. In these environments too, measurement should be used to monitor health status to support high quality care for individuals and populations. Routine and systematic person-centred measurement can also support self-management, by allowing people with long-term musculoskeletal conditions, to monitor their health longitudinally over extended time periods and share this in a standard format with health professionals.

Given the complexity and diversity of musculoskeletal conditions, it may not be practical to use a separate patient-reported outcome measure for each different condition that is seen. Therefore, in July 2012, Arthritis Research UK convened a musculoskeletal health community workshop to consider options for agreeing a standard approach to musculoskeletal patient reported outcomes. This workshop included active participation and feedback from people with arthritis, clinicians, academics and policy makers. Representatives were asked to consider how many different measures might be required to capture the musculoskeletal health of the diverse range of conditions seen in a typical clinic.

A consensus emerged that despite disease activity measures being by nature disease specific, many of the symptoms that patients with musculoskeletal conditions share are common between diseases. Symptoms such as pain, stiffness and fatigue, along with health domains such as pain interference with work and daily routine, are arguably of prime concern and common to those affected by musculoskeletal conditions. A combination of these could therefore best capture the impact of a musculoskeletal condition on an individual's health.

Following on from this meeting, Arthritis Research UK commissioned Keele University, in collaboration with the University of Oxford, to work with people with arthritis and other experts to develop a single, short questionnaire that could be completed by people with arthritis and musculoskeletal conditions to capture their "musculoskeletal health". The interim name for the instrument was the Arthritis Research UK Musculoskeletal Patient Reported Outcome Measure (M-PROM). Following input from patient representatives this subsequently was renamed the Arthritis Research UK Musculoskeletal Health Questionnaire (MSK-HQ). This reflects that for those living with a musculoskeletal conditions, their musculoskeletal health will fluctuate and change over time, and it is this that should be captured, not just the "outcome" of a particular treatment.



A

Vision for the MSK-HQ

Arthritis Research UK wants to see routine and systematic use of outcome measures such as the MSK-HQ throughout musculoskeletal health services to empower patients, support clinical decision making, drive forward quality improvement and ensure that the highest quality services are rewarded for their achievements.

Measurement of health status matters, because reliable clinical information informs and supports the behaviour of, and interactions between, patients, clinicians, managers and policymakers.

To date, PROMs have largely been used as summative measures, collected before and after a specific procedure to measure health gain attributable to the intervention. The MSK-HQ will have an important role in enabling this well-understood application of PROMs across a wide range of clinical settings. There may also be an important formative role for the MSK-HQ. Because the range of health areas in the MSK-HQ is broad – including items on mental health, independence, physical and social functioning as well symptoms – achievement in particular domains can help to guide quality improvement, supporting services to focus on improving areas of weakness.

There is another important use for PROMs. In many long-term conditions, such as high blood pressure or diabetes, measurement is already used to support high quality care. This is true both for supporting clinical decision making, and also as part of the care and support planning process, where people are supported to review their health status and agree a health plan with their clinician.

For musculoskeletal conditions, the significant measures are not biochemical or anatomical, but patient-reported ratings of symptoms and their impacts on health. Here too, the MSK-HQ can support high-quality care. By capturing an overall rating of a person's musculoskeletal health at any given time, the MSK-HQ enables patients and their clinicians to monitor progress over time and response to treatment. Considering individual components of the score, such as sleep quality or mood can allow particular aspects of musculoskeletal health to be addressed, ensuring a holistic approach to patient needs. Simply using the MSK-HQ may support people to report a wider range of their symptoms to their clinical team than they otherwise would feel able.

The MSK-HQ, therefore, has the potential to become in musculoskeletal health what “blood pressure” is in cardiovascular health, or the “HbA1c” in diabetes: an essential measure of musculoskeletal health that can be used throughout health systems for the benefit of people with musculoskeletal conditions. One that is meaningful to patients, clinicians and those who are responsible for services, and whose meaning is understood by all. One that has the potential to transform care for people living with arthritis and musculoskeletal conditions.



Development of the Musculoskeletal Health Questionnaire (MSK-HQ):

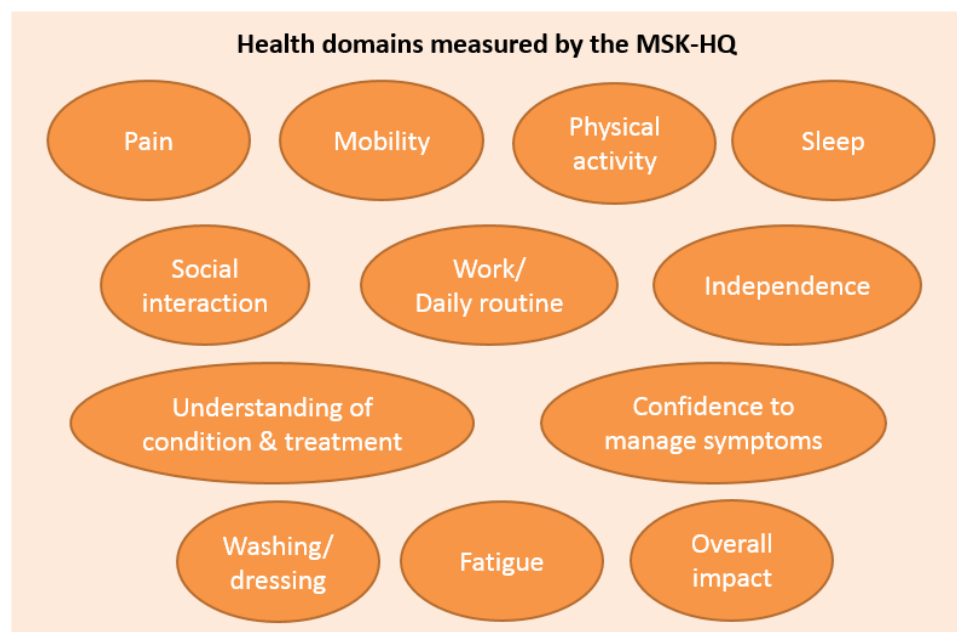
This first phase ran during 2013. It was led by Dr Jonathan Hill at the Arthritis Research UK Primary Care Unit at Keele University, supported by Professor Ray Fitzpatrick and Professor Andrew Price at the University of Oxford. The objective for this phase was to design a valid, reliable and relatively brief tool that could be used by people with a wide range of musculoskeletal conditions to report their own health at various steps along diverse treatment pathways.

Identifying and prioritising key outcomes to include in the MSK-HQ

The project began by identifying the health domains that matter most to people with musculoskeletal conditions. The team extensively reviewed the published literature describing existing patient reported outcome measures. From this, they produced a long list of musculoskeletal health constructs (or issues) that had previously been used in questionnaires. The list was refined and prioritised through successive qualitative interviews, patient focus groups and patient and stakeholder workshops. This process included participation from patients, clinicians, national musculoskeletal patient and professional body representatives and musculoskeletal researchers.

Following this consensus process, participants identified and prioritised the following key outcomes for inclusion in the MSK-HQ (in priority order):

- pain severity (in the day and night),
- physical function (walking and dressing),
- physical activity level,
- pain interference (with work/daily routine and with social activities/hobbies),
- difficulty with sleep, fatigue/low energy levels,
- emotional well-being (anxiety and mood),
- understanding of diagnosis and treatment,
- confidence to self-manage (pain self-efficacy),
- independence,
- overall impact from symptoms (bothersomeness).



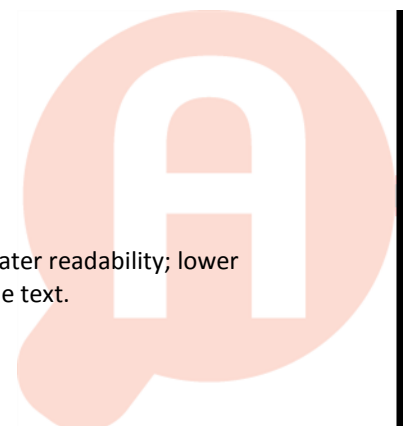
It was agreed that the MSK-HQ should include no more than 15 items and would use a response scale based on 'severity'. There was no strong difference in preferences for particular domains between patients, clinicians and other stakeholders. At the conclusion of the process there was strong endorsement across the stakeholder community for the key domains that emerged.

Developing the draft MSK-HQ

The initial stages produced a final list of prioritised musculoskeletal outcome domains. The team then formulated single items for each domain by looking at items in relevant existing questionnaires. They used an iterative process with patients to optimise the wording of these items and to ensure that the question they used had appropriately captured the domain it was chosen to represent (content validity).

Initial testing found that it typically took around two minutes for people to complete the MSK-HQ. The 'Flesch' reading ease test score¹ of the MSK-HQ was 65.9 meaning it is easily understood by 13-15 year old students. It is easier to read than many PROMs such as the EQ-5D-5L which scores 61.3.

¹ The 'Flesch' reading ease test is automated test where a higher score indicates greater readability; lower scores suggest a higher level of educational attainment is needed to comprehend the text.



Piloting the Musculoskeletal Health Questionnaire (MSK-HQ):

The second phase of the piloting work began in the spring of 2014. It was led by Professor Andrew Price and Professor Ray Fitzpatrick at the University of Oxford, funded jointly by NHS England and Arthritis Research UK. The objective of this phase was to examine how the MSK-HQ can be used in practice while at the same time further understanding its psychometric properties.

The team explored using the MSK-HQ in three types of clinical settings and one commissioning setting. The clinical settings were chosen to broadly represent the diversity of settings in which the MSK-HQ was intended to be used:

- people referred for orthopaedic surgery on their knee, hip or shoulder
 - Oxford Nuffield Orthopaedic Centre
- people receiving treatment from community physiotherapy,
 - Middlewich
 - Congleton
 - Wombourne
 - Cheadle
 - Wolverhampton
- people attending rheumatology outpatient clinics with inflammatory/rheumatoid arthritis
 - Kings College Hospital;
 - Newcastle;
 - Lancashire;
 - Guys and St Thomas' NHS Trust;
 - Pennine MSK

In the clinical arm, the emphasis was further validation to better understand the properties and performance of MSK-HQ including looking at the completion rate, test-retest reliability, construct validity, internal reliability and responsiveness.

All patients completed the candidate MSK-HQ along with the EQ-5D-5L. In addition, patients completed condition-specific questionnaires:

- Orthopaedic cohort: Oxford Hip Score (OHS), Oxford Knee Score (OKS), Oxford Knee Score-Activity & Participation Questionnaire (OKS-APQ) and Oxford Shoulder Score (OSS) for hip, knee and shoulder problems respectively,
- Physiotherapy cohort: six-item Keele MSK-PROM²
- Rheumatology cohort: *To be confirmed.*

The second arm of the pilot employed qualitative methods to understand how managerial and commissioning decisions are affected by the availability of outcomes data from collection of the MSK-HQ. Bedfordshire Clinical Commissioning Group was chosen as the pilot site for this. The focus here was on the real-world usefulness of the MSK-HQ to support and inform organisational and service developments. Here, case study methods were used to examine how an organisation used the new instrument (the MSK-HQ).

CircleHealth had been commissioned to provide the local musculoskeletal service using a novel prime contractor model, with a strong focus on outcomes delivery. The research team invited then to use the MSK-HQ as they saw fit in their developing service. Data for research would be collected using a mixture of scheduled interviews, access on a confidential basis to records of meetings, and summary anonymised patient data.

² Hill JC, Thomas E, Hill S, Foster NE, and van der Windt D. Development and validation of the Keele Musculoskeletal Patient Reported Outcome Measure (MSK-PROM). PLoS One. 2015; 10(4): e0124557



Findings: Orthopaedic and physiotherapy pilots

This part of the pilot included 570 patients, two-thirds female (65.2%) with average (mean) age 57 years.

- 210 patients attending physiotherapy,
- 150 patients referred for hip surgery,
- 150 patients referred for knee surgery,
- 60 patients referred for shoulder surgery.

Initial complete data was available for 537/570 patients (94.2%), suggesting a high level of acceptability. Follow-up MSK-HQ scores were completed by 58.9%, which was an acceptable response rate.

In order to assess the reproducibility of the questionnaire, a sample of 370 patients completed MSK-HQ a second time shortly after baseline completion with an average time interval of 6 days between tasks. There were 245 patients reporting 'stable' symptoms between the two time-points. Within this group with 'stable' symptoms, the MSK-HQ total score agreement ICC was 0.84, demonstrating 'excellent' reproducibility.

The validity of the MSK-HQ instrument in each of these groups was confirmed by comparing patient scores with existing validated measures at baseline and follow-up:

- There was a strong correlation between MSK-HQ and EQ-5D-5L
- There was a strong correlation between the MSK-HQ and the Oxford Hip and Knee scores
- There was a moderate correlation between the MSK-HQ and the Oxford Shoulder Score

The majority of patients rated their health as better when followed-up, with a positive effect demonstrated in both MSK-HQ and EQ-5D. It is noticeable that the change was greater when measured on the MSK-HQ. In the case of the Physio cohort (multiple conditions) greater responsiveness was shown with MSK-HQ, compared to EQ-5D.

Findings: Commissioning pilot

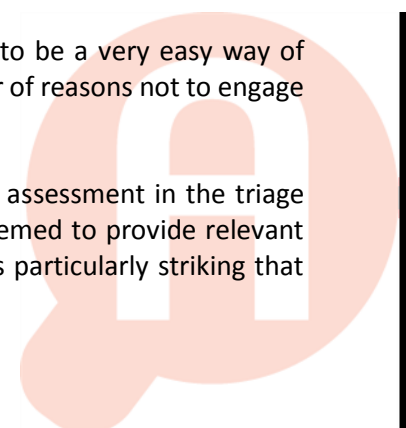
There was enthusiasm for the MSK-HQ, based on the advantage of a single measure across MSK pathways of care.

A meeting of relevant Circle managers identified patients with shoulder and back pain as a focused manageable group of patients about whom they were keen to learn more about. Fairly quickly this was further refined down to a more manageable group – patients presenting with shoulder problems.

The MSK-HQ was offered to 146 patients presenting at the triage "hub", who were approached by phone, before attending the service. Of these, 22 declined to participate. Recruitment by phone was not generally thought to be a very easy way of obtaining participation, because respondents could identify any of a number of reasons not to engage when called 'out of the blue', including being too busy.

For the clinician immediately involved in administering it before and after assessment in the triage system, the new questionnaire was found to be acceptable to patients, seemed to provide relevant content and provided positive evidence of the value of the service. It was particularly striking that

'Actually it makes sense if you are trying to run a whole pathway or managing an entire pathway if you have got one measure tracking the entire pathway its good. When we heard certainly about one measure for the whole of it [MSK], it makes logical sense.' (Senior manager, Circle).



items that would not be standard elements of many health status instruments such as understanding of the condition and of treatments, and confidence in managing their condition, seemed particularly relevant to the clinician.

The MSK-HQ scores showed substantial improvement in patient health after 3 months, and both front-line and managerial staff considered the MSK-HQ to be a valuable tool in providing relevant feedback about services. The logic of the MSK-HQ as a single, validated musculoskeletal PROM was sufficiently clear that the senior manager was willing to consider proposing it to the CCG in future contracts.

This one limited case study found broad positive support for the relevance and potential usefulness of the MSK-HQ, and conversely no important reported problems, in the use of the MSK-HQ to support a range of decisions to improve the provision of musculoskeletal services.

It would help us compare providers more consistently because there are different providers using things a different way.... The EQ-5D, I think you can do that, but it's a bit clunky...and although it's a quality of life measure, it's more generic whereas this is more [specific] to muscular conditions.

Analysis for Questions 12, 13, 14 ... showed that confidence increased, understanding of condition increased and overall impact of condition decreased (improved).



Ongoing piloting work

The process of piloting the MSK-HQ generated considerable interest from the health and care community. A number of commissioners and providers approached Arthritis Research UK, asking if they could start to use the MSK-HQ as part of their routine service provision. The requests were largely driven by the growing interest in measuring and demonstrating quality and value of services.

To make sure that learning could be captured from these early pilots, the research team worked with Arthritis Research UK to create a “piloting partners” collaboration, via the Oxford CLAHRC (Collaboration for Leadership in Applied Health Research and Care). This will take the form of a further short case study of 9 or 10 ‘partners’ (a range of NHS services and organisations) who over a year will implement MSK-HQ in a wide range of real world contexts, in a ‘learning set’ jointly to identify and share lessons about the use of MSK-HQ:

1. Boroughs Partnership Trust – Physiotherapy
2. British School of Osteopathy – Whole pathways of care
3. Dorset – Patient decision aids in knee replacement pathway
4. Evesham Community Hospital – Physiotherapy services
5. NHS Scotland Musculoskeletal Services – Physiotherapy, podiatry, orthotics
6. Nottingham – Sports and exercise medicine
7. Sandwell and West Birmingham - Physiotherapy and physio-led triage
8. Sussex MSK partnership (Central) – Spinal pathways initially, then others
9. Sussex MSK partnership east – Elective orthopaedic surgery
10. University Hospital South Manchester – Physiotherapy outpatients

This project with MSK-HQ partners will provide broader evidence of uptake and impact.

The emphasis here is to observe and learn from non-research environments. There has been no additional resource, staffing or expertise supplied to these partners that might artificially amplify uptake and impact of MSK-HQ. Instead, the aim is to understand.



National context for MSK-HQ

To deliver high quality care and high value services, the NHS needs to capture the health status of patients and measure the outcomes of interventions. Previously, this was difficult in musculoskeletal health services because of the lack of a standard, agreed measurement to use. Now there is now a clear opportunity to embed the MSK-HQ into routine clinical practice across the NHS and wider care system.

Accountability in the England NHS is through the various outcomes frameworks, through the Outcomes Indicator Set (CCG-OIS) for clinical commissioning groups and the NHS Outcomes Framework (NHS-OF) nationally. Currently, though outcomes of hip and knee surgery are included, there are substantial gaps which can now be filled. The MSK-HQ can be used to fill this measurement gap to provide data that the NHS and musculoskeletal health community needs.

Routinely collected and collated MSK-HQ scores from groups of patients can be used to understand if the healthcare they receive is effective in improving musculoskeletal health outcomes. MSK-HQ should therefore be used as an **outcome measure for musculoskeletal health** within local and national outcomes frameworks, including at individual service level.

Professional society endorsements

As part of the work engaging with professional bodies about the MSK-HQ, both the Royal College of General Practitioners (RCGP) and the Chartered Society of Physiotherapy (CSP) have agreed to endorse the MSK-HQ.



New directions for the MSK-HQ

The creation of a reliable, valid, feasible, acceptable MSK-HQ generates many new questions to be answered and opportunities to be explored.

Supporting self-management

There are now clinical and research groups looking into whether people with arthritis and musculoskeletal conditions can use the MSK-HQ to help them manage their own health. This includes incorporating the MSK-HQ in the systems and processes for *Care and Support Planning*, or developing platforms for people to use the MSK-HQ to support *health literacy, preparation for clinic appointments* or as part of *shared decision making* tools. For example, it could be possible for people to access the MSK-HQ on a website, app or patient-held clinical record and share this with their clinical team.

Supporting data collection

Arthritis Research UK has worked with the Health and Social Care Information Centre (HSCIC) to make sure the MSK-HQ can be simply captured in clinical records. As a result, there are now both SNOMED CT terms and Read codes for the MSK-HQ that should enable this.³ In the long term, it should be possible to include this in the dataset for care data.

Health checks at work

University Hospitals Southampton plan to use the MSK-HQ in their staff “health checks” as part of the NHS England ‘spearhead’ site initiative, working to improve the health and wellbeing in NHS staff.

Getting hold of the MSK-HQ

The MSK-HQ is available online via General Info: <http://isis-innovation.com/health-outcomes/> and a Licence request: <http://process.isis-innovation.com/>

³ <https://isd.hscic.gov.uk/trud3/user/guest/group/0/home>



Appendix A: Draft MSK-HQ instrument



ARTHRITIS RESEARCH UK MUSCULO-SKELETAL HEALTH QUESTIONNAIRE (MSK-HQ)

This questionnaire is about your **joint, back, neck and muscle symptoms** such as aches, pains and/or stiffness.

Please focus on the particular health problem(s) for which you sought treatment from this service.

For each question **tick (✓) one box** to indicate which statement best describes you **over the last 2 weeks**.

1. Pain/stiffness during the day How severe was your usual joint or muscle pain and/or stiffness overall during the day in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Fairly severe <input type="checkbox"/>	Very severe <input type="checkbox"/>
2. Pain/stiffness at night How severe was your usual joint or muscle pain and/or stiffness overall at night in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Fairly severe <input type="checkbox"/>	Very severe <input type="checkbox"/>
3. Walking How much have your symptoms interfered with your ability to walk in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Severely <input type="checkbox"/>	Unable to walk <input type="checkbox"/>
4. Washing/Dressing How much have your symptoms interfered with your ability to wash or dress yourself in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Severely <input type="checkbox"/>	Unable to wash or dress myself <input type="checkbox"/>
5. Physical activity levels How much has it been a problem for you to do physical activities (e.g. going for a walk or jogging) to the level you want because of your joint or muscle symptoms in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Very much <input type="checkbox"/>	Unable to do physical activities <input type="checkbox"/>
6. Work/daily routine How much have your joint or muscle symptoms interfered with your work or daily routine in the last 2 weeks (including work & jobs around the house)?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Severely <input type="checkbox"/>	Extremely <input type="checkbox"/>
7. Social activities and hobbies How much have your joint or muscle symptoms interfered with your social activities and hobbies in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Severely <input type="checkbox"/>	Extremely <input type="checkbox"/>

Arthritis Research UK MusculoSkeletal Health Questionnaire (MSK-HQ)

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8. Needing help How often have you needed help from others (including family, friends or carers) because of your joint or muscle symptoms in the last 2 weeks?	Not at all <input type="checkbox"/>	Rarely <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Frequently <input type="checkbox"/>	All the time <input type="checkbox"/>		
9. Sleep How often have you had trouble with either falling asleep or staying asleep because of your joint or muscle symptoms in the last 2 weeks?	Not at all <input type="checkbox"/>	Rarely <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Frequently <input type="checkbox"/>	Every night <input type="checkbox"/>		
10. Fatigue or low energy How much fatigue or low energy have you felt in the last 2 weeks?	Not at all <input type="checkbox"/>	Slight <input type="checkbox"/>	Moderate <input type="checkbox"/>	Severe <input type="checkbox"/>	Extreme <input type="checkbox"/>		
11. Emotional well-being How much have you felt anxious or low in your mood because of your joint or muscle symptoms in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Severely <input type="checkbox"/>	Extremely <input type="checkbox"/>		
12. Understanding of your condition and any current treatment Thinking about your joint or muscle symptoms, how well do you feel you understand your condition and any current treatment (including your diagnosis and medication)?	Completely <input type="checkbox"/>	Very well <input type="checkbox"/>	Moderately <input type="checkbox"/>	Slightly <input type="checkbox"/>	Not at all <input type="checkbox"/>		
13. Confidence in being able to manage your symptoms How confident have you felt in being able to manage your joint or muscle symptoms by yourself in the last 2 weeks (e.g. medication, changing lifestyle)?	Extremely <input type="checkbox"/>	Very <input type="checkbox"/>	Moderately <input type="checkbox"/>	Slightly <input type="checkbox"/>	Not at all <input type="checkbox"/>		
14. Overall impact How much have your joint or muscle symptoms bothered you overall in the last 2 weeks?	Not at all <input type="checkbox"/>	Slightly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Very much <input type="checkbox"/>	Extremely <input type="checkbox"/>		
15. Physical activity levels In the past week , on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? <i>This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.</i>							
None <input type="checkbox"/>	1 day <input type="checkbox"/>	2 days <input type="checkbox"/>	3 days <input type="checkbox"/>	4 days <input type="checkbox"/>	5 days <input type="checkbox"/>	6 days <input type="checkbox"/>	7 days <input type="checkbox"/>

Finally, please check back that you have answered each question. Thank you very much.

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