

**Response to The Government's mandate to NHS England for 2017/18, Annex 7.3. From the musculoskeletal Data Advisory Group.**

December 2017

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## Opening Remarks

### **Prof Peter Kay, National Clinical Director for Musculoskeletal Conditions, NHS England**

The NHS has an important role in supporting people to maintain, improve and restore musculoskeletal health. One in five of the population sees a general practitioner every year about a musculoskeletal problem. Care for these conditions amounts to £4.7 billion, the third largest NHS England programme budget. There is now recognition that people being able to work is an important health outcome that the NHS must support. These recommendations from the musculoskeletal health community will support NHS England to improve musculoskeletal health and work data. Through understanding the gaps in our knowledge and addressing the data challenges, we can do more to support people with arthritis to stay in or return to work.

### **Prof John Newton, Head of Health Improvement, Public Health England**

The scale and impact of musculoskeletal conditions is huge and require a public health approach. This must be built upon high quality data about who is affected by which conditions, how this affects health and wellbeing, and what health and care services (including public health) are doing to maintain and restore health. Meaningful work is important to health, and better data about work will help services improve their support for people to enter, return to and remain at work. The recommendations in this report are a welcome attempt to agree core data items which – if brought together – could transform our understanding of musculoskeletal health.

### **Prof Tony Woolf, Chair, ARMA**

In the UK in 2016, 30.8 million working days were lost because of musculoskeletal problems. Only two thirds of working age people with a musculoskeletal condition are in work. Most people with these conditions want to be in work, and with the appropriate support they can. People with musculoskeletal conditions can benefit from health and care services, from employers' support, from occupational health services, and from other services aimed at enabling people to return to work. What gets measured gets done so it's important that work features strongly in these recommendations developed collaboratively by the whole musculoskeletal community, of which ARMA is the umbrella body. By learning more about the connections between musculoskeletal health and work, these data can improve the support they provide and transform work and health outcomes for people living with musculoskeletal conditions.

### **Dr Liam O'Toole, CEO, Arthritis Research UK**

The pain, stiffness and fatigue of arthritis affect every aspect of a person's home and work life. Most people with arthritis want to work and with the right support they can; but often can't get the support they need when they need it. Arthritis Research UK is dedicated to improving the quality of life for people with arthritis. Because we believe that better data will support this, we are delighted to have led this project working closely with musculoskeletal sector colleagues. We look forward to working in with NHS England and others towards improved services that support people with arthritis to live and work in good health.



## Overview of Recommendations

Musculoskeletal conditions, such as arthritis and back pain, are the largest cause of pain and disability in England. Affecting over 10 million people, they are responsible for over 30 million working days lost each year. Care for these conditions accounts for the third largest area of NHS programme spend at £4.7 billion.

To improve services, the NHS needs high-quality data about the prevalence of these conditions, the treatments and services provided to people living with them, and the outcomes of that care. There is a growing recognition of the important and reciprocal relationship between work and health. To improve health and work outcomes, the NHS needs reliable data, which it can then act upon. Yet, for various reasons, there is a historic lack of data about musculoskeletal (MSK) conditions in the NHS.

The need to address this was recognised in the 2017/18 NHS Mandate in which NHS England was asked to “work with Government to identify opportunities for regular collection of data about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England”.

To support NHS England in responding to the mandate, Arthritis Research UK created an advisory group, bringing together professional and patient organisations, policymakers and researchers. Chaired by Dr Benjamin Ellis, supported by Michael Ly, the group met regularly in the second half of 2017, recommending six data items whose collection should be prioritised. These are presented in order of logical progression, starting with the basic required information:

	What we want to know	Data item	Immediate next steps
1	How many people are presenting with MSK conditions?	Nature of presenting musculoskeletal conditions among people aged 16-75 years.	<b>IMPLEMENTATION</b> <ul style="list-style-type: none"> <li>• Include “type and site” data in Community Services Dataset (CSDS)</li> </ul>
2	Of those presenting with an MSK condition, what is the impact on their health?	Health status of people aged 16-75 years presenting with an MSK condition (e.g. MSK-HQ)	<b>IMPLEMENTATION</b> <ul style="list-style-type: none"> <li>• Include outcome measure, such as MSK-HQ, in CSDS</li> </ul>
3	Of those presenting with an MSK condition, how many are in paid work?	Employment status of people aged 16-75 years presenting with an MSK condition.	<b>PILOTING</b> <ul style="list-style-type: none"> <li>• Link to existing Joint Work and Health unit activity to pilot questions in CSDS</li> </ul>
4	Of those presenting with an MSK condition who are in work, what is the impact on their work?	Proportion presenting with an MSK problem reporting current work interference.	<b>PILOTING</b> <ul style="list-style-type: none"> <li>• Pilot collection of Work Productivity and Activity Impairment</li> </ul>



			Questionnaire (WPAI) in CSDS
5	What proportion of work absence of a week or more is attributable to MSK conditions?	Improved MSK health data collection and coding in fit notes.	<b>IMPLEMENTATION</b> <ul style="list-style-type: none"> <li>• Improve data quality, e.g. agree standardised and consistent nomenclature for MSK problems</li> </ul>
6	What support are those presenting with an MSK condition who are struggling to work, or who are out of work, receiving?	Capture any support received to remain at or return to work	<b>RESEARCH</b> <ul style="list-style-type: none"> <li>• Commission research to develop a new instrument validated and piloted in NHS settings</li> </ul>

Information provided to the advisory group suggested that the immediate opportunity to address some of these data issues is through the Community Services Data Set (CSDS) which electronically collects data from Community Services that are funded and/or provided by the NHS or local authorities. Although this will not capture information about the many people with musculoskeletal conditions accessing health care through their GP only, substantial numbers of people with musculoskeletal conditions are seen by allied health professionals (AHPs, such as physiotherapy, podiatry, occupational therapy) in community settings. As a relatively new dataset for adults, CSDS is being actively improved, and there is room for development, with the possibility of including survey tools. Items 1 and 2 could rapidly be included in CSDS, and piloting of items 3, 4 could be initiated quickly in discrete areas, then evaluated for wider rollout.

Similarly, work could begin immediately on item 5. It should be a priority for work to be commissioned to agree tractable improvements to musculoskeletal condition coding in fit notes. This work should take place alongside other activities to improve the quality of the fit note, including completion of fit notes by allied health professionals. The success of these activities will depend on successful professional engagement so that clinicians have the skills, willingness and time to record high-quality data.

In the longer term, the aim should be to extract item 1 from general practice records. This would capture data from more people who engage with health services, providing a much better overall picture of musculoskeletal health and its associations with work participation. The current system for extracting general practice data, GPES, is at capacity and there is no realistic prospect of these items being extracted in the coming years. Successor systems should address these capacity issues. In the meanwhile, preparatory work could now be funded in targeted local areas to test how data extracted from GP records systems could be analysed and converted into usable intelligence for the NHS.

Item 1 could in theory be extracted from routine general practice data, whereas items 2, 3, and 4 would require new data collections. Although this may be feasible and, indeed, desirable in some general practice settings such as Care and Support Planning, it is unlikely to be practicable or acceptable in routine general practice appointments without dedicated funding. Future work on patient-held records, such as that underway at RCGP, may facilitate patient entry of patient-reported outcome measures, and the advisory group



recommended that inclusion of musculoskeletal health and work data should actively be considered in this context.

The final item, item 6, is a research recommendation. NHS England should play an active role in facilitating the development of this, bringing together potential public sector funders, such as the National Institute for Health Research (NIHR), with charity sector funders, academics and NHS organisations. The aim of this is to secure funding, and engage participating NHS organisations to develop a new data collection tool, measure its reliability and validity and undertake the necessary implementation research.

Individually, each of these data items is important; together, they will paint a powerful picture of the interrelation between musculoskeletal health and work. Each item will require specific activities to make it a reality. Some items can be implemented fairly rapidly, at least in some settings. Others will require more work, particularly to extend these items to general practice. By making rapid gains in community settings for allied health professionals through CSDS, and building over successive years, NHS England can transform services for people with arthritis and other musculoskeletal conditions.



# Introduction

## Background

Musculoskeletal conditions are the greatest cause of years lived with disability in the UK.<sup>1</sup> These conditions affect over 10 million people, are responsible for over 30 million working days lost each year,<sup>2</sup> and care for these conditions accounts for the third largest area of NHS programme spend at £4.7 billion.<sup>3</sup>

High-quality data are needed to understand population health needs and to be able to plan for how these can be met. This includes work on health promotion and prevention, as well as for the delivery of health and care services. National and local data about services activity and health outcomes allows evaluation of policy changes, highlight unwarranted variation, and support innovation, better integration and quality improvement activity.

There is, however, a lack of high-quality data about people with musculoskeletal conditions within health and care services. This may be because these conditions are difficult to measure (often not having simple biomarkers) because their impact is predominantly on morbidity rather than mortality, which has not been prioritised for data collection. This is because much of the care is delivered in primary and community care settings, where data collection and extraction are less robust than inpatient care. Cumulatively, these risk inequity and missed opportunities to improve the quality of musculoskeletal health and care services.

Furthermore, the failure to record, link and share data within the NHS, with partners such as local authorities, social care, and the lack of use of relevant administrative datasets (such as those on statutory benefits) may compromise the care and safety of patients, limit capacity to evaluate and improve services, and hamper aspirations to conduct world-class research.

**Data and the Life Sciences Industrial Strategy:** As part of the Government's Industrial Strategy, Sir John Bell led a review of the life sciences to understand the future challenges and support requirements of this sector of the economy. His independent report, *Life Sciences: industrial strategy*, features data as one of seven central themes and sets forth a series of recommendations for improvements in the quality, collection and use of data within the NHS. These recommendations include the development of therapy-area-specific national data registries, created and aligned with relevant charities.

## Health and work for people with musculoskeletal conditions

Musculoskeletal conditions are the UK's second leading cause of sickness absence, only behind minor illnesses. In 2016, 30.8 million working days were lost in the UK due to

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<sup>1</sup> Institute for Health Metrics and Evaluation (IHME). GBD Compare Data Visualization. Seattle, WA: IHME, University of Washington, 2016. Available from <http://vizhub.healthdata.org/gbd-compare>. (Accessed [11.12.2017]).

<sup>2</sup> Office for National Statistics (ONS). Sickness Absence Report 2016. Available from <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2016>

<sup>3</sup> NHS England 2013/14 CCG programme budgeting benchmarking tool. Available from <https://www.england.nhs.uk/resources/resources-for-ccgs/prog-budgeting/>



musculoskeletal problems.<sup>4</sup> Only two-thirds of working-age people with a musculoskeletal condition are in employment. Stiffness and pain can make everyday tasks in the workplace difficult and may slow people down. Pain can lead to low mood, affecting motivation to work and ability to concentrate.<sup>5</sup> The unpredictable, fluctuating nature of musculoskeletal symptoms makes it more difficult to plan work, and to implement strategies to address difficulties.

Many people with musculoskeletal conditions want to work and, in the right job with the right occupational and health support, are able to overcome these challenges. To comply with the Equality Act 2010, employers must take reasonable steps to make adjustments for disabled people, including people with arthritis and musculoskeletal conditions. People must be supported to work in roles that are meaningful, fulfilling, flexible, and adapted to their skills and capabilities.

Advice and support from health and care professionals in relation to work, together with clear communication between health and care systems and employers, can inform people's choices and provide support about remaining in, or returning to, work. However, work is not yet routinely considered as a clinical outcome, nor is work status routinely recorded in health records.

There is an 'employment gap' in relation to people with musculoskeletal conditions, in that fewer people with these conditions are in work, compared to people with no condition or disability. The employment rate for people with musculoskeletal conditions (62.4%) is almost 20% lower than the employment rate of people with no condition or disability (80.4%).<sup>6</sup> Two out of five (43%) of working-aged people with arthritis report that their condition has a negative impact on their working life.<sup>7</sup> One in four people (25%) with arthritis report retiring earlier from work than they otherwise would have.<sup>8</sup> To understand and then address the underlying determinants, we need better routine data about the health and work experiences of people with musculoskeletal conditions.

### **The Government's Work, Health and Disability Green Paper**

*Improving Lives: the Work, Health and Disability Green Paper* was published jointly by the Department for Work & Pensions and the Department of Health in October 2016. The Green Paper highlighted the health and work barriers experienced by people with arthritis. This included references to Arthritis Research UK's *Care Planning and musculoskeletal conditions* report, work by the Chartered Society of Physiotherapy on waiting times for musculoskeletal services and case studies from the National Rheumatoid Arthritis Society. The impact of arthritis and musculoskeletal conditions on working lives was recognised throughout the narrative, highlighting that: "Over half (54%) of all disabled people who are out of work experience mental health and/or musculoskeletal conditions as their main health condition"<sup>9</sup>

The Green Paper also included four specific commitments relevant to musculoskeletal conditions: on care planning, new models of healthcare, employment services and data.

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<sup>4</sup> Office for National Statistics (ONS). Sickness Absence Report 2016. Available from <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2016>

<sup>5</sup> McGee R et al (Sep 2010). Exploring the connection between physical and mental health conditions.

<sup>6</sup> Labour Force Survey. Quarterly Statistics Q2 April-June 2017.

<sup>7</sup> Arthritis Care (2014). Arthritis Nation 2014. A report from Arthritis Care on the pain of arthritis.

<sup>8</sup> Arthritis Research UK/ESRO (TBC). Everyday life and arthritis.

<sup>9</sup> Department for Work and Pensions and Department of Health. Work, Health and Disability Green Paper Data Pack, 2016.





Among these, it identified ... *a lack of detailed information about what kinds of musculoskeletal services are currently commissioned, and the extent to which the services meet local need. The government will therefore work with NHS England to **identify opportunities for regular collection of data** about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England.*

### **NHS England Mandate 2017/18**

Following the *Improving Lives: Work, Health and Disability* Green Paper the Department of Health published the *NHS Mandate 2017 to 2018* in March 2017. As part of the objective to support research, innovation and growth, included in the Health and Work commitments, the mandate featured a commitment on data collection for musculoskeletal conditions – “to *work with Government to identify opportunities for regular collection of data about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England*”.



## Existing Data about Musculoskeletal Health and Work

The following is a list of existing data sources that have relevance to both musculoskeletal health and work. It briefly describes the relevance, and the main advantages and disadvantages with regards to the mandate commitment.

Large scale population studies/survey's	Description	Relevance	Advantages	Disadvantages
<b>Health survey for England (HSE)</b>	<ul style="list-style-type: none"> <li>Survey on health status and lifestyles of people living in England.</li> <li>All ages</li> <li>NatCen Social Research</li> <li>1991-ongoing (annual)</li> </ul>	<ul style="list-style-type: none"> <li>Drug abuse, alcohol and smoking</li> <li>General health (<i>condition specific information such as musculoskeletal conditions</i>)</li> <li>Health services and medical care</li> <li>Mental health</li> <li>Nutrition</li> <li>Physical fitness and exercise</li> <li>Social attitudes and behaviour</li> </ul>	<ul style="list-style-type: none"> <li>Ability to add new questions and survey's.</li> <li>Widespread health data topics.</li> <li>Existing information on work status.</li> </ul>	<ul style="list-style-type: none"> <li>Only a subsample of the population, not the true real-time prevalence.</li> <li>No regular collection of MSK related data, including questions around persistent pain and joints involved.</li> </ul>
<b>General Lifestyle Survey (GLS)- previously known as the General Household Survey</b>	<ul style="list-style-type: none"> <li>Survey of people living in private households in Great Britain.</li> <li>Aged 16+</li> <li>ONS</li> <li>1971-2011 (annual-longitudinal four yearly rotation)</li> </ul>	<ul style="list-style-type: none"> <li>Household information (<i>accommodation, housing costs, etc.</i>)</li> <li>Employment</li> <li>Pensions</li> <li>Health</li> <li>Childcare</li> <li>Smoking and Drinking</li> <li>Financial situation</li> <li>Income</li> <li>Family Information (marriages, cohabitations, fertility)</li> </ul>	<ul style="list-style-type: none"> <li>Number of people reporting arthritis.</li> <li>Able to link health data with employment and financial status (income etc.)</li> </ul>	<ul style="list-style-type: none"> <li>No longer being conducted</li> <li>Data not broken down into type of arthritic condition.</li> </ul>
<b>General Practice Patient Survey (GPPS)</b>	<ul style="list-style-type: none"> <li>Experience of care and services patients received from their GPs surgery in England.</li> <li>Aged 18+</li> <li>Ipsos Mori, NHS England</li> <li>2008-onwards (annual)</li> </ul>	<ul style="list-style-type: none"> <li>Overall patient experience</li> <li>Access to in-hours GP services</li> <li>Online GP services</li> <li>Waiting times</li> <li>Confidence and trust</li> <li>Opening hours</li> <li>Managing your health</li> </ul>	<ul style="list-style-type: none"> <li>Information on care received by people with LTCs.</li> <li>Number of people reporting arthritis/long-term joint problem or back pain available.</li> </ul>	<ul style="list-style-type: none"> <li>Data not broken down into specific conditions.</li> <li>No links to work outcomes.</li> </ul>

		<ul style="list-style-type: none"> <li>■ Care planning</li> <li>■ NHS Dentistry results</li> </ul>		
<b>English Longitudinal Study of Aging (ELSA)</b>	<ul style="list-style-type: none"> <li>■ Longitudinal survey of ageing and quality of life among older people in England.</li> <li>■ Aged 50+</li> <li>■ 2002-ongoing (every two years)</li> <li>■ NatCen Social Research, Manchester university, UCL, Institute for Fiscal Studies</li> </ul>	<ul style="list-style-type: none"> <li>■ Individual &amp; household demographics</li> <li>■ Health (including social care)</li> <li>■ Social participation</li> <li>■ Work and pensions</li> <li>■ Income and assets</li> <li>■ Housing and consumption</li> <li>■ Cognitive function (assessment)</li> <li>■ Expectations</li> <li>■ Effort and reward</li> <li>■ Psychosocial health</li> <li>■ Consents</li> <li>■ Timed walk (60+)</li> <li>■ Self-completion</li> </ul>	<ul style="list-style-type: none"> <li>■ Number of people with MSK conditions by type.</li> <li>■ Links to work and health status.</li> <li>■ Widespread health related data.</li> </ul>	<ul style="list-style-type: none"> <li>■ Restricted to people aged 50+.</li> <li>■ Only a subsample of the population-not the true real-time prevalence.</li> </ul>
<b>The Health and Employment After Fifty (HEAF)</b>	<ul style="list-style-type: none"> <li>■ Cohort study of 8,000 adults recruited from 24 English GP practices part of the CPRD.</li> <li>■ Aged 50-64 years</li> <li>■ 2013-2016</li> <li>■ Medical Research Council (MRC)</li> </ul>	<ul style="list-style-type: none"> <li>■ Demographic and anthropometric characteristics</li> <li>■ Current work status</li> <li>■ Content and characteristics of paid work</li> <li>■ Perceptions about work</li> <li>■ Perceptions about retirement</li> <li>■ Financial status</li> <li>■ Social</li> <li>■ Health</li> </ul>	<ul style="list-style-type: none"> <li>■ Information on impact of MSK conditions on work.</li> <li>■ Linked up to CPRD.</li> </ul>	<ul style="list-style-type: none"> <li>■ Data available for three years only.</li> <li>■ Restricted to people aged 50-64 years.</li> </ul>



<p><b>Understanding Society</b> (also known as UK Household Longitudinal Study UKHLS)</p>	<ul style="list-style-type: none"> <li>■ Longitudinal study of 40,000 households in the UK.</li> <li>■ Aged 16+ (incl. self-completed youth questionnaire for members aged 10-15 years)</li> <li>■ 2009-ongoing</li> <li>■ Institute for Social and Economic Research (ISER)</li> </ul>	<ul style="list-style-type: none"> <li>■ Basic demographic characteristics</li> <li>■ Social characteristics</li> <li>■ Employment &amp; work characteristics</li> <li>■ Childcare, other caring within and outside household</li> <li>■ Life satisfaction</li> <li>■ Transport and communication access</li> <li>■ Financial status</li> <li>■ Housing</li> <li>■ Household</li> </ul>	<ul style="list-style-type: none"> <li>■ Prevalence of arthritis or certain MSK relevant impairments.</li> <li>■ Key source for understanding individual-level transitions/changes in health and employment status over time.</li> </ul>	<ul style="list-style-type: none"> <li>■ Limited to information on arthritis (health condition) or certain relevant impairments (problems with mobility, lifting or carrying, or manual dexterity).</li> </ul>
<p><b>Labour force survey (LFS)</b></p>	<ul style="list-style-type: none"> <li>■ Survey of the employment circumstances of the UK population.</li> <li>■ Aged 16+</li> <li>■ 1973-ongoing (annual-quarterly data available)</li> <li>■ ONS</li> </ul>	<ul style="list-style-type: none"> <li>■ Individual demographic characteristics</li> <li>■ Household</li> <li>■ Family structure</li> <li>■ Basic housing information</li> <li>■ Household member demographic characteristics</li> <li>■ Economic activity</li> <li>■ Employment</li> <li>■ Work related illness</li> <li>■ Education</li> <li>■ Health</li> </ul>	<ul style="list-style-type: none"> <li>■ Employment status of people with MSK conditions over time.</li> <li>■ Potential to examine co-occurring conditions</li> <li>■ Impact of health condition on work/changes in employment.</li> </ul>	<ul style="list-style-type: none"> <li>■ Limited breakdown on type of MSK condition; information indicates site of problem</li> </ul>



<b>Annual Population Survey (APS)</b>	<ul style="list-style-type: none"> <li>▪ A continuous sample based household survey on approx. 320,000 members of the UK population (uses data from LFS)</li> <li>▪ Aged 16+</li> <li>▪ 2004-ongoing (annual-quarterly data available)</li> <li>▪ Includes a longitudinal element</li> <li>▪ ONS</li> </ul>	<ul style="list-style-type: none"> <li>▪ Demographic characteristics</li> <li>▪ Ethnicity</li> <li>▪ Religion</li> <li>▪ Employment status</li> <li>▪ Economic activity</li> <li>▪ Workplace characteristics</li> <li>▪ Health condition or disability</li> </ul>	<ul style="list-style-type: none"> <li>▪ Trends in employment status of people with MSK conditions.</li> <li>▪ Key source for understanding employment rates of people with MSK conditions or other health conditions.</li> <li>▪ Data available at local authority level.</li> <li>▪ Potential to examine co-occurring conditions.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Limited breakdown on type of MSK condition; information indicates site of problem.</li> </ul>
<b>Health service data extracts</b>	<b>Description</b>	<b>Relevance</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>Hospital Episode Statistics (HES)</b>	<ul style="list-style-type: none"> <li>▪ Data warehouse containing details of all admissions, outpatient appointments and A&amp;E attendances at NHS hospitals in England.</li> <li>▪ All ages</li> <li>▪ Ongoing</li> <li>▪ NHS Digital</li> </ul>	<ul style="list-style-type: none"> <li>▪ Demographic characteristics (age, gender)</li> <li>▪ Primary Diagnosis, main procedures &amp; interventions</li> <li>▪ Emergency</li> <li>▪ Waiting List</li> <li>▪ Bed days</li> </ul>	<ul style="list-style-type: none"> <li>▪ Data linkage opportunities via NHS number (i.e. CSDS, GP data, prescribing data, NJR, ONS, PROMS).</li> </ul>	<ul style="list-style-type: none"> <li>▪ Limited to care provided in NHS hospitals.</li> <li>▪ The first point of contact for patients with MSK conditions is primary care or community care.</li> </ul>
<b>The Health Improvement Network (THIN) database</b>	<ul style="list-style-type: none"> <li>▪ Anonymised longitudinal patient records from over 500 GP practices.</li> <li>▪ All ages</li> <li>▪ 2003-ongoing</li> <li>▪ UCL</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patient demographics</li> <li>▪ Medical diagnosis</li> <li>▪ Therapy</li> <li>▪ Additional Health Data</li> <li>▪ Postcode Variable Indicators</li> <li>▪ Consultation</li> <li>▪ Staff</li> </ul>	<ul style="list-style-type: none"> <li>▪ Routinely collected primary care data.</li> <li>▪ Number of people with MSK conditions by type.</li> </ul>	<ul style="list-style-type: none"> <li>▪ The richness of GP data often lost in free text.</li> <li>▪ Data only covers 6.2% of the UK GP registered population.</li> </ul>
<b>The Consultations in Primary Care Archive (CiPCA)</b>	<ul style="list-style-type: none"> <li>▪ Pseudoanonymised medical record data from a subset of general practices in North Staffordshire</li> <li>▪ All ages</li> <li>▪ Keele University -Research Institute for Primary Care &amp; Health Sciences</li> </ul>	<ul style="list-style-type: none"> <li>▪ Demographic characteristics</li> <li>▪ Consultation</li> <li>▪ Prescriptions</li> <li>▪ Investigations</li> <li>▪ Referrals</li> </ul>	<ul style="list-style-type: none"> <li>▪ Consultation prevalence of MSK conditions by type.</li> <li>▪ Good quality GP level data.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Only covers North Staffordshire population profile.</li> </ul>



	<ul style="list-style-type: none"> <li>2000-ongoing</li> </ul>			
<b>The Clinical Practice Research Datalink (CPRD)</b>	<ul style="list-style-type: none"> <li>Anonymised patient medical record data from &gt;800 general practices in the UK.</li> <li>All ages</li> <li>1987-ongoing (monthly)</li> <li>NIHR, MHRA</li> </ul>	<ul style="list-style-type: none"> <li>Demographic and anthropometric characteristics</li> <li>Medical diagnosis</li> <li>Referrals</li> <li>Prescriptions</li> <li>Immunisations/vaccinations</li> <li>Diagnostic</li> <li>Lifestyle (smoking, alcohol)</li> <li>Other care</li> </ul>	<ul style="list-style-type: none"> <li>Number of people with MSK conditions by type.</li> <li>Linkage opportunities-HES and mortality data.</li> </ul>	<ul style="list-style-type: none"> <li>Self-reported conditions such as back pain not as well recorded.</li> <li>Doesn't capture data on health and work.</li> </ul>
<b>Community Services Data Set (CSDS)-</b> <i>supersedes the CYPHS data set, to allow adult community data to be submitted</i>	<ul style="list-style-type: none"> <li>Record level data on people accessing community-based or allied health professional services.</li> <li>All ages</li> <li>NHS Digital</li> </ul>	<ul style="list-style-type: none"> <li>Demographic and anthropometric characteristics</li> <li>Social and personal circumstances</li> <li>Breastfeeding and nutrition</li> <li>Care event and screening activity</li> <li>Diagnoses, including long-term conditions and disabilities</li> <li>Scored assessments</li> <li>Referral</li> </ul>	<ul style="list-style-type: none"> <li>Dataset currently has room for development such as incl. survey tools.</li> <li>Improved tool will actively include data from AHP care for MSK patients.</li> <li>Linkage opportunities with HES, fit note, etc. via NHS number.</li> </ul>	<ul style="list-style-type: none"> <li>Only capturing information about people visiting AHPs/community services.</li> <li>Need to ensure provider compliance and regular submission of data.</li> </ul>
<b>Fit notes</b>	<ul style="list-style-type: none"> <li>Data on electronic fit notes issued by GPs in England.</li> <li>Aged 18-65 years</li> <li>2012-ongoing</li> <li>NHS Digital, Work and Health Unit</li> </ul>	<ul style="list-style-type: none"> <li>Patient demographics</li> <li>Diagnosis (reason for sickness)</li> <li>Episodes</li> <li>Duration</li> </ul>	<ul style="list-style-type: none"> <li>Provides link between impact of MSK health on work and work absence.</li> <li>Collected electronically, therefore room for improvements and coding.</li> </ul>	<ul style="list-style-type: none"> <li>Linkage currently not possible as no identifiable data (i.e. NHS number) is collected.</li> <li>Information around work status not included (only advice upon return to work).</li> </ul>
<b>Work related datasets</b>	<b>Description</b>	<b>Relevance</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>The Health and Occupation Research Network in General Practice (THOR-GP)</b>	<ul style="list-style-type: none"> <li>GP level data from a select number of GPs (~250-300) returning information on cases of work-related ill health and sickness absence in England.</li> <li>Aged 16+</li> <li>2005-ongoing</li> </ul>	<ul style="list-style-type: none"> <li>Demographic characteristics</li> <li>Diagnosis</li> <li>Symptoms</li> <li>Occupation</li> <li>Industry</li> <li>Causative agent</li> </ul>	<ul style="list-style-type: none"> <li>Link between health and work specifically work related MSK conditions.</li> </ul>	<ul style="list-style-type: none"> <li>Small dataset.</li> <li>Limited geographical spread.</li> <li>Some specialities no longer providing data.</li> </ul>



	<ul style="list-style-type: none"> <li>▪ HSE, University of Manchester</li> </ul>			
<b>Incapacity benefits</b>	<ul style="list-style-type: none"> <li>▪ Data on people in receipt of incapacity benefits to replace income for people out of work with a health condition/disability.</li> <li>▪ Incapacity benefits include: Employment and Support Allowance, Incapacity Benefits, Severe Disablement Allowance</li> <li>▪ 2008-ongoing (annual/quarterly/cumulative)</li> <li>▪ DWP</li> </ul>	<ul style="list-style-type: none"> <li>▪ Claimant demographics</li> <li>▪ Payment durations</li> <li>▪ Main health/disabling condition</li> </ul>	<ul style="list-style-type: none"> <li>▪ Scale of MSK conditions among people receiving welfare benefits.</li> <li>▪ Potential for linkage with surveys and other sources to understand employment outcomes for people with MSK conditions.</li> <li>▪ Some data available at local authority level.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Limited condition- specific breakdowns currently published.</li> <li>▪ No information collected on employment or other support received.</li> </ul>
<b>Disability benefit data</b>	<ul style="list-style-type: none"> <li>▪ Data on people in receipt of disability benefits (Personal Independence Payment, Attendance Allowance) to support with extra costs of disability</li> <li>▪ PIP data from 2013 (quarterly)</li> <li>▪ DWP</li> </ul>	<ul style="list-style-type: none"> <li>▪ Claimant demographics</li> <li>▪ Main health/disabling condition</li> </ul>	<ul style="list-style-type: none"> <li>▪ Scale of MSK conditions among people receiving welfare benefits.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Limited condition- specific breakdowns available; PIP includes the categories 'musculoskeletal disease: general'; 'musculoskeletal disease: regional'.</li> </ul>
<b>Registers &amp; audits</b>	<b>Description</b>	<b>Relevance</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>National Joint Registry (NJR)</b>	<ul style="list-style-type: none"> <li>▪ Register of information on all hip, knee, ankle, elbow, and shoulder replacement operations in England, Wales, Northern Ireland and the Isle of Man</li> <li>▪ All ages</li> <li>▪ 2003-ongoing (annually)</li> <li>▪ National Joint Registry.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Demographic characteristics</li> <li>▪ Procedure &amp; surgical details</li> <li>▪ Outcomes</li> <li>▪ Mortality</li> </ul>	<ul style="list-style-type: none"> <li>▪ Possibility to link to PROMs or other health status measures.</li> <li>▪ Includes care provided by non-NHS providers.</li> </ul>	<ul style="list-style-type: none"> <li>▪ No links between health and work.</li> <li>▪ Limited to data on joint replacements.</li> </ul>
<b>BSR Biologics Registrar for Rheumatoid Arthritis (BSRBR)</b>	<ul style="list-style-type: none"> <li>▪ Register of patients with rheumatological disorders treated with biologic agents in the UK (~20,000 people registered)</li> <li>▪ Aged 16+</li> <li>▪ 2001-ongoing</li> <li>▪ University of Manchester</li> </ul>	<ul style="list-style-type: none"> <li>▪ Demographic and anthropometric characteristics</li> <li>▪ Risk factors</li> <li>▪ Health</li> <li>▪ Treatment</li> <li>▪ Working status</li> </ul>	<ul style="list-style-type: none"> <li>▪ Links between biologic use, health, and work.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Voluntary registry.</li> <li>▪ Limited to people with rheumatological disorders receiving biologics or biosimilar treatments.</li> </ul>



<b>National Hip Fracture Database (NHFD)</b>	<ul style="list-style-type: none"> <li>■ Web-based audit of hip fracture care in England, Wales and Northern Ireland.</li> <li>■ Aged 60+</li> <li>■ 2007-ongoing</li> <li>■ RCP, HQIP part of FFFAP</li> </ul>	<ul style="list-style-type: none"> <li>■ Patient demographics</li> <li>■ Inpatient falls</li> <li>■ Fracture management</li> <li>■ Surgery</li> <li>■ Length of Stay</li> <li>■ Follow-up</li> <li>■ Mortality</li> <li>■ Rehabilitation</li> </ul>	<ul style="list-style-type: none"> <li>■ Links between hip fracture and health status.</li> </ul>	<ul style="list-style-type: none"> <li>■ Limited to people who have had a hip fracture.</li> <li>■ No link between health and work.</li> </ul>
<b>National Audit of Inpatient Falls (NAIF)</b>	<ul style="list-style-type: none"> <li>■ Organisational and clinical audit of inpatient falls and care provided in acute hospitals in England and Wales</li> <li>■ Aged 65+</li> <li>■ 2010-ongoing (annual)</li> <li>■ RCP, HQIP part of FFFAP</li> </ul>	<ul style="list-style-type: none"> <li>■ Occupied bed days</li> <li>■ Number of falls</li> <li>■ Policies, protocols, paperwork</li> <li>■ Case notes (assessment)</li> <li>■ Patient care/environment</li> </ul>	<ul style="list-style-type: none"> <li>■ Total occupied bed days and number of falls reported in acute hospitals.</li> </ul>	<ul style="list-style-type: none"> <li>■ Limited to people over 65 years suffering from falls in acute hospitals.</li> <li>■ No link between health and work.</li> </ul>
<b>Rheumatoid and early inflammatory arthritis national audit</b>	<ul style="list-style-type: none"> <li>■ Audit of assessment received by patients referred to rheumatology services with suspected inflammatory arthritis in England and Wales.</li> <li>■ Aged 16+</li> <li>■ 2014-ongoing (annual)</li> <li>■ HQIP</li> </ul>	<ul style="list-style-type: none"> <li>■ Patient demographics</li> <li>■ Referral time</li> <li>■ Waiting time</li> <li>■ Quality of Care</li> <li>■ Support self-care</li> <li>■ Impact</li> <li>■ Experience of care</li> </ul>	<ul style="list-style-type: none"> <li>■ Impact of early arthritis on patient's health status (RAID, DAS) and work.</li> <li>■ Health professionals asking patients about work during consultations.</li> </ul>	<ul style="list-style-type: none"> <li>■ Specific to patients with inflammatory arthritis.</li> <li>■ Small sample size</li> </ul>





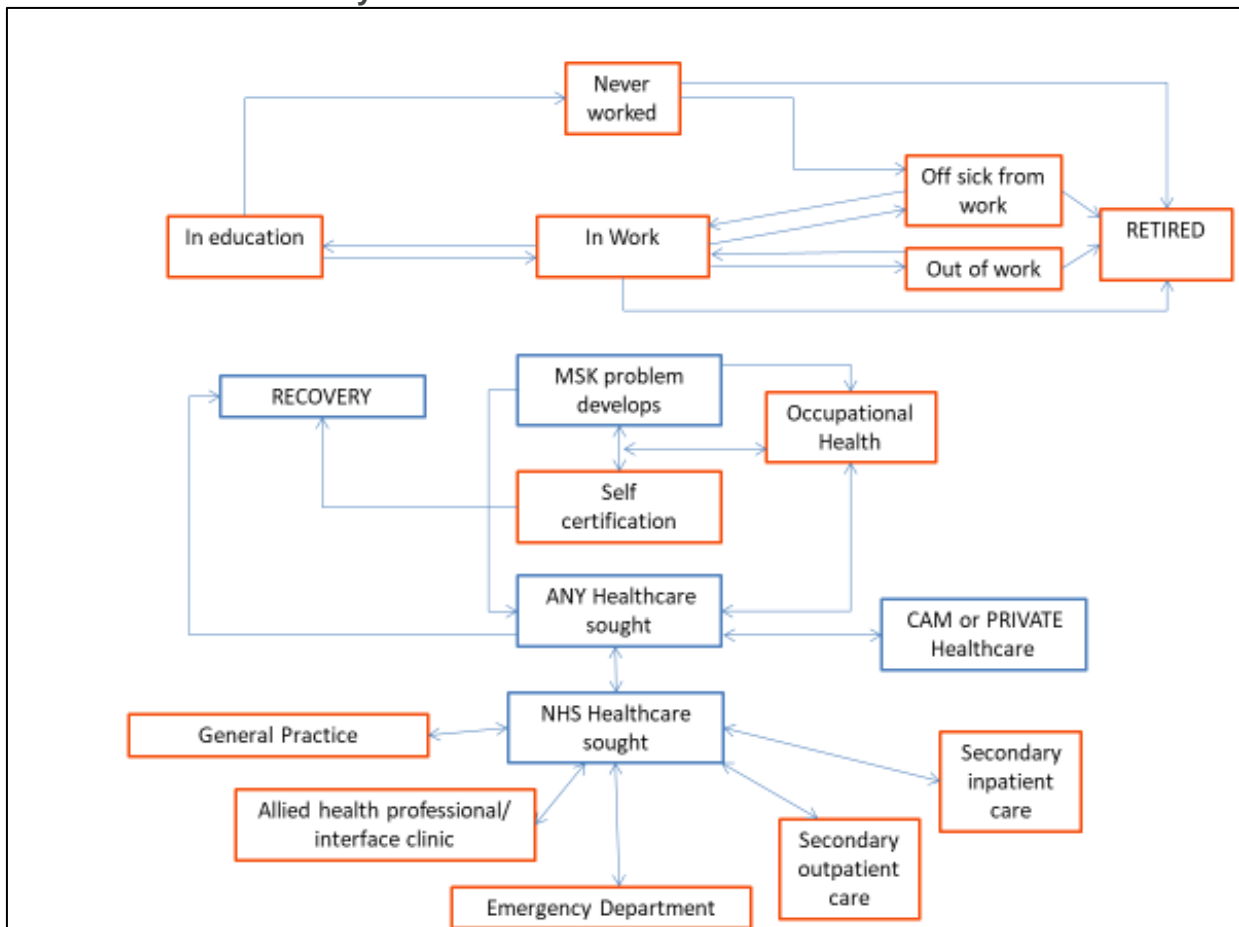
## Musculoskeletal Data Advisory Group

To support NHS England in responding to this, Arthritis Research UK created an advisory group, bringing together professional and patient organisations, policymakers and researchers. Chaired by Dr Benjamin Ellis, supported by Michael Ly, the group aimed to prioritise 3-5 opportunities for data collection that will be both trackable and impactful, and lead to higher value services and better outcomes for people with musculoskeletal conditions, with the intention that these could be rapidly piloted and evaluated. The terms of reference for the group are in Appendix A and the membership of the group in Appendix B. The group met regularly in the second half of 2017, recommending that six data items be prioritised by NHS England for collection. Over the course of the work, several important interdependencies were identified:

### Clinical Settings

At the beginning of the process, the advisory group considered what clinical settings across the musculoskeletal pathway we would like to have data to fully understand the experience of health and work. This health and work journey (Figure 1) looked at both the clinical pathway (the orange boxes) and the health experience (the blue boxes). The advisory group subsequently considered each of the clinical settings to generate a long list of indicators (Appendix C) and then to determine what was in scope for the mandate to NHS England.

**Figure 1**  
**Health and Work Journey**



### Community Services Data Set

The Community Services Dataset (CSDS) electronically collects data from Community Services that are funded and/or provided by the NHS or local authorities. Substantial numbers of people with musculoskeletal conditions are seen by the allied health professionals in community settings, such as physiotherapists, podiatrists, and occupational therapists. Allied health professionals are increasingly accustomed to recording and reporting data such as patient reported outcome measures (PROMs) which are often required for contractual purposes. As a relatively new dataset for adults, CSDS is being actively improved, and there is room for development including inclusion of survey tools.

**There is therefore a substantial and immediate opportunity to prioritise improved musculoskeletal health and work data through CSDS.**

### Case Study - Scotland AHP MSK Waiting Times Data Set

In an effort to reduce waiting times and deliver better outcomes for patients, the Scottish Government have developed a National AHP Musculoskeletal (MSK) 4 Week Target. From 1 April 2016 onwards, at least 90% of patients should receive a first clinical out-patient appointment (either by face-to-face, telephone, or video) with an Allied Health Professional (AHP) for Musculoskeletal (MSK) conditions within 4 weeks from referral.

Scottish NHS boards have since developed systems to collect this information and quarterly publications are produced on waiting times for all adult MSK services delivered by AHPs in Physiotherapy, Occupational Therapy, Chiropody/Podiatry and Orthotics. As well as informing local performance the data has been used in the development of trajectories and to evidence board reporting to secure resource allocation where applicable. The data is shared with other national programmes, for example, the Orthopaedic Service Development Group, to support a collaborative approach to planning and delivery.

These data are still in their early stages of development and progress is continuously being made with all boards to improve completeness and quality of the data to measure performance faithfully. Other information reported includes, referrals per head of population, mode of contact, body part and also Did Not Attend Rates.

### Data collection from general practice

In theory the general practice health record is a rich source of data. In practice, the current NHS system for extracting data (GPES, the general practice extraction service) is at full capacity with no short-term possibility of this changing. There are significant projects underway through NHS digital to address these issues, so that in future years more extensive data extraction will be possible. For this to be useful, however, work will need to be done to improve the quality and standardisation of musculoskeletal condition coding and terminology within the general practice record, so that the data extracted will be meaningful. Furthermore, given current pressures on general practice and competing national priorities, general practitioners are unlikely to support new data collection – such as patient questionnaires on work on health – without dedicated funding and support.



### **Case study – Ealing Primary Care Standard**

Ealing CCG wanted to ensure it was maximising its ability to improve access for patients, reduce unwarranted variation in health outcomes and ensure long-term sustainability in the local health system. It therefore put in place 23 new standards of care, the 'Ealing Primary Care Standard', that focuses on the delivery of high-quality care in general practice. The standards are underpinned by metrics that will demonstrate improved health outcomes.

One standard focuses on musculoskeletal conditions. Priorities in primary care musculoskeletal healthcare, identified in the JSNA, include increasing physical activity in all ages, referrals to falls prevention programmes, reducing unwarranted variation in referral rates between GP practices and improve links between NHS and return to work schemes.

One component of the Ealing Standard advises to "Refer people off work for a musculoskeletal condition for more than four weeks, when clinically appropriate, to the 'Fit for Work' scheme or an equivalent occupation health review". The metric underpinning this standard is: "The percentage of people off work for more than four weeks with a musculoskeletal problem referred for an occupational health or Fit for Work assessment".

The standards go live in April 2018. In the first year, the metrics will be used to develop a benchmark. In subsequent years, the effect of GP education and training to support this standard can be assessed. Ultimately, this standard will help contribute to reducing health-related worklessness due to musculoskeletal disorders. This is reported in the Quarterly Labour Force Survey published by the Office for National Statistics, albeit not in small area geographies.

### **Recording of employment status in health records**

Unemployment and poor-quality work are linked to worse health outcomes, therefore improving access to good work is a key public health concern.<sup>10</sup> There is widespread consensus that work should now be considered a health outcome. This led to a commitment in the *Improving Lives: Work, Health and Disability* Green Paper to develop an information standard to collect employment status in healthcare datasets. This work is being taken forward by the Joint Work and Health Unit. Discussions are underway about which are the best questions to be asked, and in which format and context. Because of the importance of the interaction between musculoskeletal health and work, there is an opportunity perhaps through CSDS, to pilot early recommendations from this work in services for people with musculoskeletal conditions.

### **Non-NHS funded care**

Many people with musculoskeletal problems access non-NHS funded services, including when employers contract occupational health and allied health professional services for their staff. To gain a fuller understanding of work and health, data from private health and care services should be coordinated with data from NHS care. The long-run aspiration should be to link these datasets, and make both available for analysis.

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<sup>10</sup> The Work Foundation (15.02.2017). What do we mean by 'work as a health outcome'? [Blog post]. Available from <http://www.theworkfoundation.com/2017/02/15/work-health-outcome/>



During 2017, small and large-scale private providers and insurers as well as professional bodies have met several times to understand how quality could be measured in private musculoskeletal care, identifying the hurdles and opportunities, plus how practically to achieve alignment for the private sector. The group has taken into account parallel NHS musculoskeletal care developments and is seeking shared approaches where sensible, while remaining mindful of value and practical considerations for private patients and clinicians. The group will share its findings and recommendations in early 2018.

### **Wider data considerations**

Several data considerations apply across recommendations, including the need for a minimum demographic dataset including age, sex, and other demographic and socioeconomic characteristics alongside all indicators; the utility of unique identifiers such as the NHS number to allow data linkage across all relevant health and care pathways, and to existing datasets such as HES, NJR, CPRD, or NHFD; and ensuring adequate consent for secondary uses of data. Data will be missing from individuals who have not consented the use of their data to be used for purposes beyond their direct care and the implications of this should be considered.

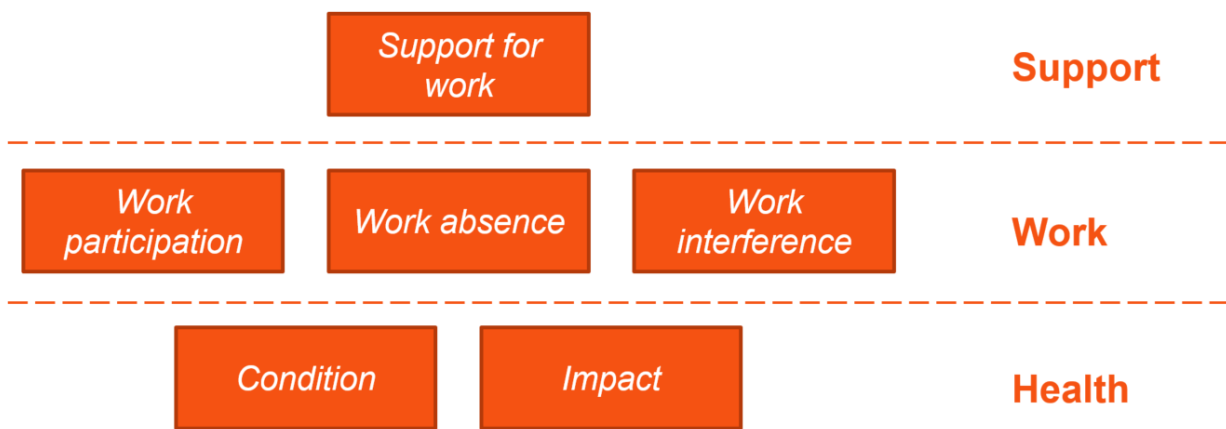


## The Recommendations

The advisory group's recommendations fall into three categories. At the heart of these are data items relating to work, particularly improving data from fit notes about work absence, but also collecting new data about work participation and work interference. Sitting beneath this, there must be a foundation of high-quality data about musculoskeletal conditions and their impact. Without this foundation being addressed, it will be difficult to make full use of the other data items. Finally, higher quality data on the support people receive for work should help drive improvements in the care and services they receive.

Individually each of these data items will be valuable. They will be most powerful when brought together, and ultimately all will be required to produce an accurate assessment of work and musculoskeletal health.

**Figure 2**  
Data items recommended by advisory group



**Recommendation one:** Nature of presenting musculoskeletal conditions among people aged 16-75 years.

**Purpose:**

To identify people in England aged 16-75 years who consult a clinician for a musculoskeletal condition at a defined point in time, and defines that condition by its nature (e.g. rheumatoid arthritis, osteoarthritis, back pain etc.) and site (generalised, knee, hip, shoulder, lower back etc.).

**Rationale:**

Musculoskeletal conditions are highly prevalent and have a major impact on individuals, health systems, and social care systems, with high direct and indirect costs. These epidemiological data are needed to understand the distribution and burden of musculoskeletal conditions in the population, and to inform planning of health and care services, public health interventions, and the relationship between musculoskeletal health and work. The age range of 16-75 was chosen to capture people most likely to be in work, including those slightly older than the standard definition of the working age population (16-64).



**Considerations:**

- The value of clinical data for secondary uses depends on diagnostic accuracy, as well as the quality and extent of clinical coding (e.g. Read codes) or structured terminology such as SNOMED-CT – this may be a particular challenge for musculoskeletal conditions where both diagnosis and coding/terminology is complex;
- Data should be linked to a unique identifier across settings such as the NHS number, to allow care to be tracked over time and between settings and to avoid double-counting;
- For maximum impact, data should be linked to person characteristics, such as geography, age, sex, and other demographic and socio-economic characteristics;
- Even with these NHS data, gaps will remain in our intelligence about national prevalence of musculoskeletal conditions, particularly those who have not been in contact with the NHS. Data from patients who have made a prior objection to their data leaving the GP practice for purposes beyond their direct care will be actively excluded; data from people receiving care via privately funded services, or people that do not seek care from health services at all.

**Next steps:**

- The immediate opportunity is to collect these data from allied health professionals in community settings via CSDS; extracting this information from general practice records seems not currently possible, but remains an important future aspiration;
- Define the scope and content of standardised diagnostic coding/terminology for musculoskeletal conditions, initially prioritising settings that will provide data for CSDS;
- Clinical training and implementation activity to support accurate and complete recording of primary musculoskeletal diagnosis for clinical practitioners providing care for people with musculoskeletal conditions, initially prioritising settings that will provide data for CSDS;
- Work with a sentinel sample of general practices to agree and run routine analyses on musculoskeletal presentations to produce estimates of national activity and develop the skills and capacity for subsequent national roll. This could use existing data extracts such as CiPCA, THIN or CPRD, or work with practices that supply data to QResearch or the RCGP 'flu surveillance network;

**Recommendation two:** Musculoskeletal health status of people aged 16-75 years with a musculoskeletal condition (e.g. MSK-HQ).**Purpose:**

To measure the health-related quality of life of people aged 16-75 years that have a musculoskeletal condition.

**Rationale:**

Musculoskeletal conditions are the leading cause of years lived with disability (YLDs) and the third largest cause of disability adjusted life years (DALYs) in the UK. Musculoskeletal services aim to improve the health of people with arthritis. Health is determined by many factors including mental health, sense of independence, physical, and social functioning, as well as disease symptoms such as pain. For most musculoskeletal conditions the significant measures are not biochemical or anatomical, but patient-reported ratings of symptoms and their impacts on health and ultimately quality of life. The Musculoskeletal Health Questionnaire (MSK-HQ) is a short questionnaire that asks people to rate their symptoms –



pain/stiffness, independence, mobility, mood, sleep, ability to take part in usual activities. Health status measurement informs and supports the behaviour of, and interactions between, patients, clinicians, managers and policymakers. Differences in “health gain” between populations of people using services or receiving treatment can inform service evaluation and guide improvement.

**Considerations:**

- The immediate opportunity is to collect these data from allied health professionals in community settings via CSDS;
- The nature and structure of general practitioner consultations, and the existence of competing priorities, it would be difficult to routinely collect health status questionnaires (such as MSK-HQ) in this setting. In the future there may be new opportunities through care and support planning, or patient-held records, which should continue to be explored;
- Piloting has found MSK-HQ to be valid and reliable in community physiotherapy settings, and more sensitive to change than EQ-5D, the more commonly used measure. There is more to understand about the optimum timing for collection of baseline and follow-up MSK-HQ scores for different populations in different settings;
- It may be difficult to obtain high completion rates from all age/gender/deprivation groups, and MSK-HQ is currently only available in English;
- Other health-related quality of life measures are available and used, for example EQ-5D in the GP Patient survey, where it is possible to compare scores for those with a long-term back pain or joint problem to those without these conditions.

**Next steps:**

- The inclusion, use and recording of MSK-HQ in CSDS requires developing structured and standardised procedures for collecting this clinical information. This includes training of those that will be administering and scoring MSK-HQ, and those entering the data into clinical systems;
- There must be agreed codes and terminology to capture MSK-HQ scores in standardised (SNOMED-CT) terminology and agreement on secure central warehousing of WPAI data within NHS digital;
- As this would be new national data collection it would require an ongoing review to examine the completeness, accuracy, coverage and validity of data collected, and to evaluate how those commissioning or providing services can use the data that emerge to improve service value and outcomes for people with arthritis.

**Recommendation three:** Employment status of people aged 16-75 years with a musculoskeletal condition.

**Purpose:**

To determine what proportion of people presenting with a musculoskeletal condition are in paid work.



**Rationale:**

Compared with the general public, work participation is less among people with musculoskeletal conditions.<sup>11</sup> Only six out of ten (59.4%) of working age people (16-64 years) with musculoskeletal conditions are in work, compared to 75.5% of working age people overall.<sup>12</sup> More than one third (44%) of people with osteoarthritis retire early, give up work or reduce the hours they work because of their condition.<sup>13</sup>

Paid employment can promote good health, and there is general agreement that work should in itself be considered a health outcome and measuring this item can support this goal through identifying good practice and supporting quality improvement activities.

**Considerations:**

- The Joint Health and Work Unit is exploring how to capture work status in health records. Currently there is no agreed, validated instrument to capture these data in a format that we know will be useful;
- The Annual Population Survey (compiled from the Labour Force Survey) records information about (1) back pain, (2) neck and upper limb problems (for example, arthritis in hand joints, stiff neck) and (3) other musculoskeletal problems not condition specific. This allows a calculation of the employment rate for people with a long-term musculoskeletal condition – whether primary or secondary- compared with people who have other health conditions, or the population without conditions.

**Next steps:**

- This work is being led by the Joint Work and Health Unit, and presents a potential opportunity to pilot how employment is recorded in clinical consultations for people presenting with a musculoskeletal condition to allied health professionals in community settings;
- A longer-term aspiration would be for this data to be recorded in, and collected from, the general practice record. This faces challenges of increased general practitioner workload and the current difficulties of data extraction from this record. In the future there may be new opportunities through care and support planning, or patient-held records, which should continue to be explored.

**Recommendation four:** Work interference among people presenting with a musculoskeletal problem.**Purpose:**

To measure the impact of having a musculoskeletal problem on people's work.

**Rationale:**

Many people with musculoskeletal conditions who are in paid work are unable to perform their role as they would like to, even when present, without the necessary support. Data on such "presenteeism" should be collected alongside "absenteeism". Evidence on the extent

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<sup>11</sup> Schofield D et al. (2013). The personal and national costs of lost labour force participation due to arthritis: an economic study. BMC Public Health 13(1):188.

<sup>12</sup> Department of Work and Pensions (Feb 2015). Labour Force Survey analysis of disabled people by region and main health problem.

<sup>13</sup> Arthritis Care (2012). OA Nation 2012.





of problems with work participation will enable service planning and provision to support people with their work and health.

### Considerations

- Work interference is difficult to measure, but the Work Productivity and Activity Impairment (WPAI) questionnaire allows people subjectively to report how their condition is affecting their work. Typically, WPAI has been used mainly in academic studies and for those affected by less common inflammatory arthritis conditions (such as rheumatoid arthritis), but there are examples of its being used for more common conditions such as osteoarthritis.<sup>14</sup> Because WPAI has a recall period of seven days, it can only provide a snapshot of work interference;
- The immediate opportunity is to pilot the use of the WPAI among people with musculoskeletal conditions seeing allied health professionals in community settings, collected via CSDS;
- Collection of other data alongside WPAI would increase impact, including about type of work, seniority, hours worked; this could be reviewed in piloting;
- The nature and structure of general practitioner consultations, and the existence of competing priorities, make it difficult to routinely collect questionnaires (such as WPAI) in this setting. In the future there may be new opportunities through care and support planning, or patient-held records, and primary care data extraction.

### Next steps

- This new data collection will require piloting and testing to examine the completeness, accuracy, coverage and validity of the data collected. It must also be analysed to demonstrate usefulness to those collecting in shaping care plans and provision of local services;
- Inclusion, use and recording of WPAI in CSDS will require developing structured and standardised procedures for collecting this clinical information. This includes training of those that will be administering and scoring WPAI, and entering the data into clinical systems;
- There must be agreed codes and terminology to capture WPAI scores in standardised (SNOMED-CT) terminology and agreement on secure central warehousing of WPAI data within NHS digital.

## **Recommendation five:** Improved musculoskeletal health data collection and coding in fit notes.

### **Purpose:**

To determine what proportion of work absence of a week or more is attributable to a musculoskeletal condition.

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<sup>14</sup> Zhang, W., Gignac, M. A., Beaton, D., Tang, K., & Anis, A. H. (2010). Productivity Loss Due to Presenteeism Among Patients with Arthritis: Estimates from 4 Instruments. *The Journal of Rheumatology*, 37(9), 1805-1814. doi:10.3899/jrheum.100123.



## Rationale:

In 2016-17, 18.0% (466,556) of fit notes with a known diagnosis were for diseases of the musculoskeletal system and connective tissues, second to mental and behavioural disorders at 31.3%.<sup>15</sup> Fit notes are issued by doctors following an assessment of patients' fitness for work. Fit notes record the functional effects of their patient's condition enabling the patient and their employer to consider ways to help them return to work. Fit note data provide evidence on the extent of absenteeism and will enable service planning and provision to support people with their work and health.

The value of fit note data depends on the coverage and data quality. As of March 2017 62.4% of patients aged 18 to 65 years registered at GP practices are included in fit note data.<sup>16</sup> GP system supplier TPP currently do not provided data for practices using their system. Of the 5,603,986 issued fit notes more than half (53.9%; 3,017,819) were not mapped to an ICD-10 chapter code because they used NIS Retired Codes, no codes were provided (i.e. free text), or codes were unknown.

## Considerations:

- Fit note data can be improved by widening coverage to all general practices and by allowing physiotherapists and other allied health professionals to issue fit notes;
- Fit note data can provide information on the patterns of certification of fitness for work by GPs, but not on the patterns of long-term sickness absence from employment. Fit notes are issued for either benefit or employment purposes but currently there is no means for a GP to record the purpose of issue, nor is it a requirement for the GP to establish the employment status of the patient for fit note purposes;<sup>17</sup>
- If the consistency and quality of coding of musculoskeletal conditions was improved in fit notes, it should be feasible to link this to work status data (Recommendation 3) to identify sickness absence due to an MSK condition;
- The current breakdown of both musculoskeletal conditions and the reasons of receiving a fit note are not suitable. Agreement is needed to develop and use a standardised and consistent nomenclature for both;
- For maximum impact, data on age, sex, and other demographic and socio-economic characteristics should also be collected;
- Data will continue to be missing from those who have made a prior objection to their data being used for purposes beyond their direct care.

## Next steps:

- Understand the extent of data quality issues around condition categories and reason specifications;
- Define the scope and content of standardised diagnostic coding and nomenclature for musculoskeletal conditions and the reasons for issuing a fit note;

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<sup>15</sup> NHS Digital. Fit notes issued by GP practices, England. December 2014 - March 2017.

<sup>16</sup> NHS Digital. Fit notes issued by GP practices, England. December 2014 - March 2017.

<sup>17</sup> NHS Digital. A Guide to Fit Notes Issued by GP Practices, England. October 2017.



- Clinical training and implementation activity (including working with IT system suppliers) to support accurate and complete recording of musculoskeletal conditions and reasons for sickness absence by clinical practitioners providing the care and fit notes;
- Pilot inclusion of fit note data from Allied Health Professionals in CSDS.

**Recommendation six:** Support received to remain in or return to work among people aged 16-75 presenting with a musculoskeletal condition.

**Purpose:**

To determine whether people presenting with musculoskeletal conditions are receiving the support they need to either get into, remain in, or return to work.

**Rationale:**

Living with a musculoskeletal condition may make it difficult to work, but many people with these conditions want to work, and can do so with the right support. Knowing how many people are getting the support they need to stay in or get in to work will help improve quality of services.

**Considerations:**

- Currently, no validated tool exists to capture this information, and different questions may be required for those trying (a) to get into, (b) to remain in and (c) to return to work. Work to develop a tool could be based on local or national initiatives, for example the National Rheumatoid Arthritis Society's (NRAS) Work Matters survey (2017);<sup>18</sup>
- If a tool were developed and validated, data collection could be piloted by allied health professionals in community settings, for collection via CSDS.
- Although collecting this information in NHS settings will provide useful intelligence, there are non-clinical settings where this indicator may be even more valuable, such as the work place (i.e. employer, or occupational health), or Job Centre Plus.

**Next steps:**

- Research should be commissioned to develop, test and validate an instrument that can capture the data needed to understand the support (or lack thereof) people with musculoskeletal conditions receive to get into, remain or return to work. This will be a significant piece of work that will require appropriate support, time, resource and funding;
- Part of this work should be testing whether collecting these data in clinical settings, such as AHP care, is practicable and impactful, or whether the emphasis should be on either workplace settings or elsewhere, for example as part of assessment for statutory benefits.

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<sup>18</sup> NRAS. Work Matters Report (2017). Available from <https://www.nras.org.uk/work-survey-2017>



# Appendix A: Terms of Reference

## Background

On 31 October 2016, the Department of Work and Pensions (DWP) published '[Improving Lives: The Work, Health and Disability Green Paper](#)'. This paper outlined a commitment to musculoskeletal data collection:

*'There is also a lack of detailed information about what kinds of musculoskeletal services are currently commissioned, and the extent to which the services meet local need.*

*The government will therefore work with NHS England to identify opportunities for regular collection of data about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England.'*

This commitment was taken forward in the work section of the [NHS England mandate 2017/18](#):

*'Work with Government to identify opportunities for regular collection of data about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England.'*

Following the publication of these two commitments, Arthritis Research UK carried out a series of meetings with key stakeholders involved in data collection and management across government and the wider healthcare and musculoskeletal (MSK) sector. These discussions highlighted a number of opportunities for data collection and analysis as well as an appetite to ensure action is taken against the mandate commitment.

Following consultation with Sarah Marsh, Policy Lead for Long Term Conditions, Clinical Policy and Strategy Team, NHS England (NHSE), it was decided that a 'task and finish' advisory group would be formed across the MSK sector in order to support the aims of the commitment.

The aim of the Advisory Group is to identify a handful of data collection opportunities that will fulfil this commitment, and drive change and improvement for the benefit of people with a MSK condition and associated MSK healthcare services.

This is an extensive piece of work that will require external support from the Advisory Group. Arthritis Research UK will be providing secretariat support and if necessary, financial support for relevant group outputs, in order to facilitate this work-stream. This support is dependent on the outcomes and operation of the group meeting the strategic aims of Arthritis Research UK which is responsible to its Trustees.

The first advisory group meeting will take place at Arthritis Research UK's National MSK Health Data meeting taking place on Tuesday 23<sup>rd</sup> May, 2017. This will be a chance for those attending the meeting to discuss and establish some of the key ways of working for the group (see below).

## Terms of reference

This sets out the ways of working for the MSK Data Advisory Group (MSK DAG):



### **Overall aim:**

- To prioritise 3-5 opportunities for data collection that will be both trackable and impactful, and lead to higher value services and better outcomes for people with MSK conditions, with the intention that these could be rapidly piloted and evaluated.
- To draft a recommendation to NHS England for implementation to begin of one or more of these opportunities for data collection beginning April 2018/19.
- To ensure the recommendations reflect the focus of the mandate on supporting people with MSK conditions in relation to health and work and participation.

### **Other priorities of this group:**

- To ensure that any data collection is meaningful to people with MSK conditions and clinicians, useful and necessary, while minimising the burden of data collection.
- To focus on developing data collections that can be used to help improve services.
- To develop a balanced set of asks that reflects the concerns of the whole patient pathway (i.e. primary care, secondary care, outpatients and community care).
- To complete the work in time for the piloting proposal to be considered as part of the preparation of the 2018/19 NHS Mandate.
- As much as in possible, to be mindful of the impact of collecting these data does not exclude any groups.
- To ensure the opportunities identified directly link to paid employment and health.

### **General:**

- The group will aim to make positive use of existing resources on quality of musculoskeletal services which have already been produced and published by the Arthritis and Musculoskeletal Alliance (ARMA) and member organisations, as relevant.
- The group will build on existing work of the MSK Indicators Advisory Group and NHS Right Care.
- The Advisory Group will work toward a deadline of finalising the recommendations to NHS England by 1<sup>st</sup> December 2017.
- After consultation with NHS England, it is confirmed that data on unpaid work is a secondary priority, with paid work the primary focus.
- The recommendations should concentrate primarily on NHS providers, although thought should be given to non-NHS providers if there is clear added value.
- The recommendations will focus on people 16-75 years.

### **Responsibilities**

- The group will liaise with / nominate a member to report to NHS England and the DWP.
- Recognising this is a 'task and finish' working group, broadly working within the spirit of Arthritis Research UK's code of conduct and practice for committees.



## Meetings

- Arthritis Research UK will act as Secretariat to the group.
- The group will be chaired by Benjamin Ellis, Senior Clinical Policy Adviser, Arthritis Research UK.
- The group will meet, generally by teleconference, monthly, with a further one hour commitment to review materials.
- Between the meetings, Arthritis Research UK will be taking the thoughts, putting them in words, adding extra thoughts and providing summaries and ideas to share back to the group during the phone call meetings as an iterative process.
- Agendas and relevant papers will be circulated in advance for comment, and notes/action points following meetings.
- A full communication and meeting schedule to be confirmed.

## Reporting

- Regular updates will be provided to Arthritis Research UK's Senior Leadership Team and the Board, which will provide oversight and governance.
- The group will provide a formal monthly update to the MSK Clinical Network via ARMA.
- Members of the group will provide updates to their own organisations.

## Operational items

- The group will operate over a limited time to project end, expected to not exceed December 2017.
- Relevant information will be circulated to the group before meetings.
- Sharing of information and resources (including confidential materials) will be agreed by the group, and will establish how it will liaise with and inform the work of other working groups aligned to the ARMA Clinical Networks project (Fracture Liaison Services, Integrated Community Musculoskeletal Care, Workforce: education and training), and will decide on the most effective use of emailing lists to share key findings/resources identified by the group.
- The group will review these initial terms of reference including stakeholder membership and circulate any updated versions to members for agreement.



## Appendix B: Membership

Membership of the working group was flexible to ensure that it can accommodate the developing needs of the group. This meant that not all members were required to attend all meetings and others may be added for consultation purposes as required. Titles and affiliations are accurate to the time of the creation of the group.

Name	Title and organisation
Bola Akinwale	Head of Strategic Evidence, Joint Health and Work Unit
Athena Bakalexi	Joint Health and Work Unit
Ian Bernstein	General Practitioner, Ealing
Sue Brown	CEO, ARMA
Liz Brutus	Strategic Health Lead, Department of Work and Pensions
Athena Chown	Senior Public Health Intelligence Analyst, Public Health England
Rachel Clark	Strategic Development Manager (Evidence & Intelligence), National Osteoporosis Society
Sarah Deeny	Associate Director – Data Analytics, The Health Foundation
Benjamin Ellis	Senior Clinical Policy Advisor, Arthritis Research UK
Justine Fitzpatrick	Head of Epidemiology and Surveillance, Public Health England
Kelvin Jordan	Professor of Biostatistics, Arthritis Research UK Primary Care Centre, Keele University
Peter Kay	National Clinical Director for MSK Services, NHS England
Liz Lawrence	Head of Health Service Improvement, Arthritis Research UK
Liz Lingard	NHS Right Care Delivery Partner, NHS England Right Care
Michael Ly	Health Intelligence Manager, Arthritis Research UK
Sarah Marsh	Programme Manager, NHS England
James O'Malley	Policy Manager, Arthritis Research UK
Nick Pahl	CEO, Society of Occupational Medicine
Neil Parkinson	Senior Analytical Manager, NHS England Right Care
Dave Roberts	Head of Primary Care Information, NHS Digital
Sophia Steinberger	Health Intelligence Analyst, Arthritis Research UK
Rupert Suckling	Director of Public Health, Doncaster Council
Ralph Sullivan	Founding Fellow of the Faculty of Clinical Informatics, RCGP Clinical Innovation and Research Centre
Greg Swarbrick	Head of Healthcare Outcomes, BUPA
Ruth Ten Hove	Head of Research and Development, Chartered Society of Physiotherapists
Steve Tolan	Head of Practice, Chartered Society of Physiotherapists
Julia Trusler	Quality Outcomes in Orthopaedics Programme Director, British Orthopaedic Association
John Varlow	Director of Information Analysis, NHS Digital
Suzanne Verstappen	Reader, Arthritis Research UK Centre for Epidemiology, University of Manchester
Karen Walker-Bone	Associate Professor in Occupational Rheumatology, Centre for Musculoskeletal Health and Work, University of Southampton
Louise Warburton	GP with special interest, Keele University and Telford MSK Service
Tony Woolf	Chair, ARMA
Mark Yates	Research Fellow, British Society for Rheumatology



## Appendix C: Long-list of indicators

The following is a long list of all the indicators and data suggestions from the SurveyMonkey questionnaire. We asked the advisory group, 'At each setting, what is the most important question we would like to know the answer to?'

### Results

The following are the answers from the SurveyMonkey questionnaire:

#### Never worked

1. What has stopped them working: choice, retirement, a medical problem. Would they like to work?
2. How many people out of work have never worked – and is it due to an MSK condition?
3. How many people who are no longer working are of working age? How many are no longer working due to MSK conditions? What is actively being done to support people of working age back into the workplace?
4. Are there certain types of work that have a higher association with leaving work in MSK patients? Does educational attainment have an association with leaving work? Does socioeconomic status have an association with leaving work?
5. What are the loss of earnings due to MSK-related work loss?
6. Proportion of people in receipt of statutory benefits who report being out of work due to their musculoskeletal condition (and nature of condition e.g. body part).
7. Proportion of people in receipt of statutory benefits who report being out of work due to their musculoskeletal condition, who also report a mental health problem.

#### Workplace

1. What support is available from line manager and colleagues?
2. What is the burden of clinic and physio appointments on MSK patients, in terms of missing work?
3. Is your workplace adapted to support your MSK problems? What is the availability/flexibility of adaptations at work?
4. Is there a cause in the workplace making the MSK issue worse?
5. Amount of fiscal incentive awarded to employers to provide (MSK focused) occupational health services to employees - by sector, by size of employer
6. Number of episodes and total duration of sickness absence due to MSK conditions - by sector, by size of employer (current survey data on this is quite weak)
7. Estimated presentism due to MSK conditions.
8. Number of employers - by sector, by size of employer – providing MSK-related reasonable adjustments (this is a legal requirement)
9. Proportion of employees who report a persistent/recurrent musculoskeletal problem (with definition/description of problem)





10. Proportion of those employees reporting a persistent/recurrent musculoskeletal problem (with definition/description of problem) who have missed work in the last year due to their musculoskeletal problem
11. Mean/median time between an employee requiring time off due to a musculoskeletal problem and return to previous role
12. Proportion of people requiring absence due to a musculoskeletal problem who do not return to their previous role
13. Proportion of employees who report a persistent/recurrent musculoskeletal problem that have requested workplace adjustments
14. Need to capture data on sick days, reasons why, prevention opportunities, access to self-care, self-management information and access to occupational health,
15. A need to understand indicators and workplaces.

### **Occupational health**

1. Is occupational health available to the individual? For what groups/occupations is occupational health data available?
2. What are the prevention opportunities, reasons for referral and referral to interventions?
3. Are there any estimates of absence due to MSK - if so, are MSK conditions more prevalence in particular occupations?
4. How can we minimise effects of work on this patient's MSK condition?
5. Return on investment in MSK-focused occupational health support - for employers of various sizes.
6. Numbers of occupational health practitioners (including those with MSK-related training) nationally – what is the trend over time.
7. Proportion of employees reporting a musculoskeletal problem who have consulted occupational health in one year period.

### **Self-certification**

1. How often do you have to self-certificate? (Defined time-scale? 12 months?)
2. Reason for self-certification.
3. What data is available on sickness absence due to MSK conditions? Are these data reported anywhere? Can estimates be provided of levels of sickness absence due to MSK. What is the average length of time off due to MSK and how many people are having multiple short period of self-certified sickness absence?
4. What is the link between self-certificate and self-measurement?
5. Proportion of total workforce who have self-certified primarily due to a musculoskeletal problem in a 1 year period.
6. Proportion of total workforce reporting a persistent or recurrent musculoskeletal problem who have self-certified due to that problem in a 1 year period.
7. Proportion of total workforce reporting a mental health problem who self-certify due to a musculoskeletal condition in a 1 year period.



8. Proportion of total workforce reporting a persistent or recurrent musculoskeletal problem who have self-certified due a mental health problem in a 1 year period.

### **General practice**

1. Is occupational health advice in primary care?
2. Is the patient in work? How many hours a week? What are the demands of the work? What support is available?
3. What is the extent of long-term MSK conditions being managed in primary care? Can GPs help the MSK problem?
4. What is the reason for referral?
5. Capture data on sick notes/fit notes.
6. Thresholds for referrals, role of indicators for shared decision making
7. Does your GP provide useful and timely services to support you in work?
8. There needs to be a minimum coding guidance for MSK conditions. There needs to be coding which allows recording of multimorbidity and MSK component.
9. What is prescribed for pain management in people with MSK and clinical/patient outcomes?
10. What is the average number of appointments made by person based on their primary MSK condition?
11. Proportion of those with a musculoskeletal diagnosis who have received a fit note in a 1 year period.
12. Proportion of those with a musculoskeletal diagnosis who also have a mental health problem who have received a fit note in a 1 year period.
13. Proportion of those with a musculoskeletal diagnosis who have received more than 1 fit note in a 1 year period.
14. Proportion of those with a musculoskeletal diagnosis who report work impairment in a 1 year period.

### **Allied health professional/interface clinic**

1. Time from referral by GP/ED/self-referral.
2. What is the: reason for referral, time to treatment, self-care, self-management support/information and referral for interventions?
3. Are they working? Would they like to be able to work? What are the issues at work?
4. To what extent do people seek private AHP treatment due to the lack of available NHS MSK support?
5. How predictive are the MSK indicators of other health indicators? Which are the work specific indicators that need tracking?
6. Would direct and timely access to an AHP or MSK interface clinic offer you better support to manage your ability to work?
7. What is the precipitating cause and is it addressed?



8. Number/type of MSK conditions seen (coding guidance required).
9. Outcomes: clinical and patient reported and stratified by referral route.
10. Capture data on falls/fracture reoccurrence.
11. Proportion attending for a musculoskeletal problem who report current work interference due to that musculoskeletal problem.
12. Proportion attending for a musculoskeletal problem who have self-certified because of a musculoskeletal problem in the last 1 year.
13. Proportion attending for a musculoskeletal problem who have received one or more fit notes because of that musculoskeletal problem in the last year.
14. Nature of musculoskeletal problem (e.g. body part), duration of problem, severity/impact of problem (e.g. QoL measure such as MSK-HQ).
15. Proportion of people attending for a musculoskeletal problem who attribute their condition to workplace factors.
16. Proportion of people attending for a musculoskeletal problem who report having disclosed their problem to their employer.
17. Proportion of people attending for a musculoskeletal problem who report having used occupational health services with their employer.
18. Proportion of people attending for a musculoskeletal problem who report having requested a workplace adjustment from their employer.
19. Proportion of people attending for a musculoskeletal problem who are in receipt of statutory benefits including ESA, PIP, DLA, AtW, Blue badges).
20. Proportion of people attending with a musculoskeletal condition who have received local authority funding for aids and adaptations.

### **Emergency department**

1. Is the patient working, as what and how many hours per week?
2. Reason for attendance, duration of MSK condition, referral, self-care, self-management support/information.
3. How many emergency admissions are there due to MSK conditions in people of working age and what is the cost of these? Which MSK conditions are causing people to seek emergency health care? Are there any issues with data recording/quality - do we have an accurate picture of this issue?
4. Why is a MSK issue an emergency? Severity? Has it prevented you from working?
5. Proportion of people presenting with an acute musculoskeletal injury due to a work incident
6. Proportion of people presenting with an acute musculoskeletal problem who have an existing diagnosis of that problem in their GP record
7. Provision and type of pain relief offered
8. Screening for, and type of, other conditions.



### Secondary outpatient care

1. Reason for referral and outcome. Time from referral to initial treatment and link to patient outcomes.
2. Is the patient working, as what, and how many hours per week?
3. What is the impact of their condition on their work? If not working would they like to be?
4. Medication prescribed, it's cost and linked to patient outcomes. Particularly as it pertains to the use of biologic drugs.
5. What are the secondary outpatient care costs of MSK conditions in people of working age?
6. Proportion of people attending for a musculoskeletal problem who are in receipt of statutory benefits within the previous year.
7. Proportion of people attending for a musculoskeletal problem who have had a fit note for their musculoskeletal problem within the last year.
8. What is the role of indicators in shared decision making?
9. Has secondary outpatient care helped to maintain your work ability?

### Secondary inpatient care

1. Is the patient working, as what and how many hours per week?
2. What are the secondary care costs of MSK conditions in people of working age.
3. What intervention was offered? What was the length of stay?
4. How many patients admitted with an MSK complaint saw an MSK specialist prior to admission?
5. Average duration of admission following surgery.
6. Average delay in discharge to home/usual place of residence/care home.
7. What are the secondary care costs of MSK conditions in people of working age.
8. Proportion of people undergoing joint replacement surgery who are of working age.
9. Proportion of people undergoing joint replacement surgery who are of working age and report work interference due to their musculoskeletal condition.

### No longer working

1. What has stopped you from working: choice, retirement, a medical problem? Would you like to work (again) and what would help?
2. How many people who are no longer working are of working age? How many are no longer working due to MSK conditions? What is actively being done to support people of working age back into the workplace?
3. Are there certain types of work that have a higher association with leaving work in MSK patients? Does educational attainment have an association with leaving work? Does SES have an association with leaving work?
4. Rates of early retirement due to MSK conditions, age of those retiring (by sector?)



5. Loss of earnings due to MSK-related work loss.
6. Proportion of people in receipt of statutory benefits who report being out of work due to their musculoskeletal condition (and nature of condition e.g. body part).
7. Proportion of people in receipt of statutory benefits who report being out of work due to their musculoskeletal condition, who also report a mental health problem.
8. Why do you no longer work and what would help you return to work?
9. Rates of early retirement due to MSK conditions and age of those retiring. Can this be collected by sector?

