

Musculoskeletal conditions and Black, Asian and minority ethnic people: addressing health inequalities

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1 - Executive summary

This project was commissioned and funded by Public Health England through the Department of Health and Social Care's Health and Wellbeing Alliance. It included a literature review, focus groups, qualitative interviews and events to bring together the evidence and promote solutions to the inequalities we found.

Musculoskeletal (MSK) conditions are one of the most common conditions affecting people around the world and a leading cause of disability, according to the Global Burden of Health report (GBD, 2017). Some Black, Asian and minority ethnic groups in the UK are disproportionately represented due to the risk factors for musculoskeletal conditions, such as levels of physical inactivity (Cabinet Office, 2019), Vitamin D deficiency (Uday and Högl 2018), poverty (Cabinet Office, 2018), socio-economic factors, working in manual occupations (Cabinet Office, 2020), and pre-existing long-term conditions such as diabetes (BHF, 2020).

Staff from the Foundation worked with academics from the University of Bedfordshire to conduct a scoping literature review. The evidence (Ali and Abdy, 2020) we found shows that black and minority ethnic people are more likely to have some conditions, such as lupus and sickle cell disease, and have poorer experience of services. We also found some examples and suggestions of better practice, such as targeted and supported lifestyle interventions, better communication and a reduced dependence on medication.

The Foundation worked with Leeds GATE, Faith Action and other partners to secure two focus groups and a series of interviews. The findings of these sessions included the need to better promote early access to diet and exercise-based interventions, the varying quality of information, and the support needs arising from comorbidities.

The project also sought to develop a community of practice through a set of events, and an online community to continue those conversations bringing together clinicians, service users, and community workers.

2- Introduction

The project sought to better understand the inequalities affecting black and minority ethnic people in England, specifically in relation to MSK conditions and health. The purpose was to bring together the evidence base, develop those insights further through qualitative research, and identify potential solutions, alongside developing a community of practice.

MSK conditions cover a wide range of diagnoses, including:

- Arthritis
- Carpel tunnel syndrome
- Hip conditions
- Knee conditions
- Neck pain
- Low back pain
- Scoliosis
- Osteoporosis
- Lupus
- MSK conditions as a result of accident/trauma/comorbidities (such as Sickle Cell Disease)

This report presents the findings of our project. It will firstly summarise the findings from the literature review and focus groups, before presenting these in infographic form. Following this are two case studies, one from a carer and one from a service user to give greater insight and depth through examining their journeys through services. The report then highlights examples of interventions addressing MSK conditions in black and minority ethnic communities internationally, before going on to identify next steps and drawing conclusions. The methodology of the literature review is included as an appendix.

3 - Literature review

The current evidence base on inequalities is sparse, with little information on ethnicity and MSK generally available on common conditions such as arthritis, back pain or osteoporosis with the exception of lupus (Lupus UK, 2020). As part of the project we commissioned a scoping literature review to look at race, ethnicity and musculoskeletal conditions. These included arthritis, osteoporosis, back pain, neck pain, joint pain, lupus, sickle cell disease, and conditions related to injuries.

Prevalence

There is a higher prevalence of MSK conditions among some ethnic minorities compared with white people (Allison et al., 2002). The same study found MSK pain is more widespread among ethnic minorities and conclude that this may reflect social, cultural and psychological differences.

There is also some evidence of higher prevalence of some conditions associated with MSK conditions (Rees, et al., 2017, Lewis and Jawed, 2017). For example, Sickle Cell Disease is most common among people from in Africa and the Caribbean, with Nigerians being the largest population.

A study of patients living in the boroughs of Lambeth, Southwark, and Lewisham in South London found higher the prevalence of SLE was higher in black Africans from West Africa (mainly Nigeria and Ghana) when compared to Europeans, but not as high as in people of African-Caribbean origin. They explain that this may be due to the more recent migration of West Africans to the UK and the likelihood that sick individuals would not have travelled compared to African-Caribbean's who are more likely to have born in the UK or migrated when they were young (Molokhia, et al., 2001).

One study highlighted that pre-menopausal South Asian women could be a risk of developing osteoporosis in later life because of poor bone health i.e. the breaking down of bones at a quicker rate than they are being reformed (McKenna and Ludwid 2008).

Care and services

There is limited evidence explaining the barriers and facilitators to accessing MSK services and experiences through the MSK conditions pathway for black and minority ethnic communities. Cultural attitudes to pain, illness and drugs,

language needs, along with health seeking behaviours are all acknowledged as factors affecting disparities in experience and outcomes of services (Adebajo et al., 2018). There were no assessments of current education campaigns around even common conditions such as arthritis, but some papers highlighted the need to raise awareness among 'at risk populations' (Lewis and Jawad, 2017; Asnani, 2016). Socio-economic factors (education, employment and income) are also seen to be important factors contributing to inequality but the consensus is that ethnicity is an independent risk factor for increased prevalence, severity and outcome of lupus (Lewis, 2017).

There are also different cultural attitudes to pain, illness and drugs (Adebajo et al., 2018). Some studies highlighted differences in MSK pain between black, and minority ethnic groups and patients from the white ethnic group (Alison, et al., 2002). Poor interpreting and translation were also highlighted as contributors to poorer outcomes.

The literature review also found some suggestions for improving practice among professionals and community workers, such as cultural competency approaches and specific awareness campaigns focused on black and minority ethnic communities, and on healthcare professionals. The literature review identified one paper on patient education in rheumatoid arthritis and the effectiveness of the Arthritis Research Council booklet and Mind Map (Walker et al., 2007) but this is not specifically for black and minority ethnic groups.

4- Focus Groups

The Foundation worked with partners to secure two focus groups and a number of interviews with people with MSK conditions. Participants were recruited through partner organisations and received a voucher for their participation. Staff developed a set of questions and areas to explore in a semi-structured way. We discussed their experiences of accessing services, treatment, and what they feel could be done better.

The Leeds GATE focus group with Gypsy and Traveller women – 12 women attended, with ages ranging from 18 to 70. Most of the women present had arthritis, one had fibromyalgia, one had an undiagnosed condition affecting their arms which was called ‘wear and tear’. Several participants complained of other co-morbidities such as sciatica, neuropathy and mental health conditions.

Faith Action focus group – seven people participated in the focus group, all women with the youngest in the 35-44 years age group and the eldest in the 65+ group. Six of the seven were South Asian (four identified as Indian, and two as Pakistani), with one person identifying as mixed Black African and White.

Key themes that emerged from the Focus Groups

Access

Access issues came up a lot in focus groups. Several people had missed appointments because letters had not arrived or were delivered to the wrong addresses. Many of the participants were not able to read, and the clinical language of letters confused almost everyone present. The result of this is that it can take several attempts to get into a service. It is clear that the Leeds GATE centre serves the community in helping them arrange appointments, reading letters, and filling in forms for health, benefits and other services.

There was a recurring theme of difficulty in getting appointments, and increased waiting times if a particular doctor had been requested, which was seen to compound the above issue of consistency. Participants described being on hold for multiple hours whilst waiting to talk to reception, and then the phone being cut off.

Lack of information and quality of communication

Most of the participants at the Leeds GATE session felt they did not understand or know enough about their conditions, their causes and effects. For example,

several wanted to know whether their conditions were genetic and would affect other family members. Others wanted to know about comorbidities such as impact on teeth. Several had not been informed about how their conditions may develop, including the person with fibromyalgia who was told to look up her condition online by a clinician. Almost everyone was unaware of the side-effects they would experience from the medication they were on.

Participants at the Faith Action focus group expressed frustration with the inconsistency in the quality of care by GPs. “Good” care generally meant clear communication regarding diagnosis and treatment, and quick referrals to the right places. In one case it took 5 years of repeated visits to the GP regarding the same symptoms until a referral was made, leading to a diagnosis of arthritis and treatment. “3 or 4” different doctors had been seen during this time, before the participant requested a particular “good” doctor, who made the correct referral. “I wish I’d been told what condition I had. I was given a piece of paper but I wasn’t actually verbally told face to face. That would have made a big difference.”

Treatment

None of the participants at the Leeds GATE session felt they had an influence on their treatment. Almost everyone had been prescribed pain medication, which was generally felt to be quite poor in terms of effectiveness and side effects. One participant talked about how the medication was so strong that when she took it she was unable to do anything for days. Another commented that recreational drugs like cannabis would be better as they would have fewer side effects and would have a greater impact on the pain experienced. A few had been prescribed or advised to engage in exercise, such as fitness classes, which had mixed results. Several participants spoke about poor experiences of care, including doctors who would not listen to them, and therapy sessions that focused on the pain ‘being in your head’. One participant spoke about being effectively confined to her bed because of the treatment, and this leading to isolation and depression.

In some cases, participants were thankful for prescriptions of painkillers, but wished they had been prescribed sooner. Generally, there was a resentment towards painkiller medications and their side effects.

Participants at the Faith Action focus group generally had some involvement in decision making around treatment, but also made their own choices regarding use of painkillers independent from medical professionals. A number of

improvements to conditions were seen to be due to decisions made independently – e.g. attendance of yoga or fitness classes, and joining community groups, etc. One person said: “Pain management was helpful, but I could have been told about exercise opportunities. I had to go out and find them myself.” Some found unexpected barriers to participating in physical activity. For example, one person needed special footwear to exercise, and it took a long time to get it. Another person found exercise was transformative to her condition, but had waited six months on pain medication before this was suggested.

Coping strategies

Most participants had come up with some ways of coping, such as using hot water bottles and microwave-heated products on their joints. One participant at the Leeds GATE session said she’d greatly benefitted from being on a diet without flour and sugar – this was something she’d done herself in order to lose weight, but she said it had had a significant impact on her experience of arthritis and she’d been able to reduce her medication. Everyone was interested in what else could be done to improve their symptoms.

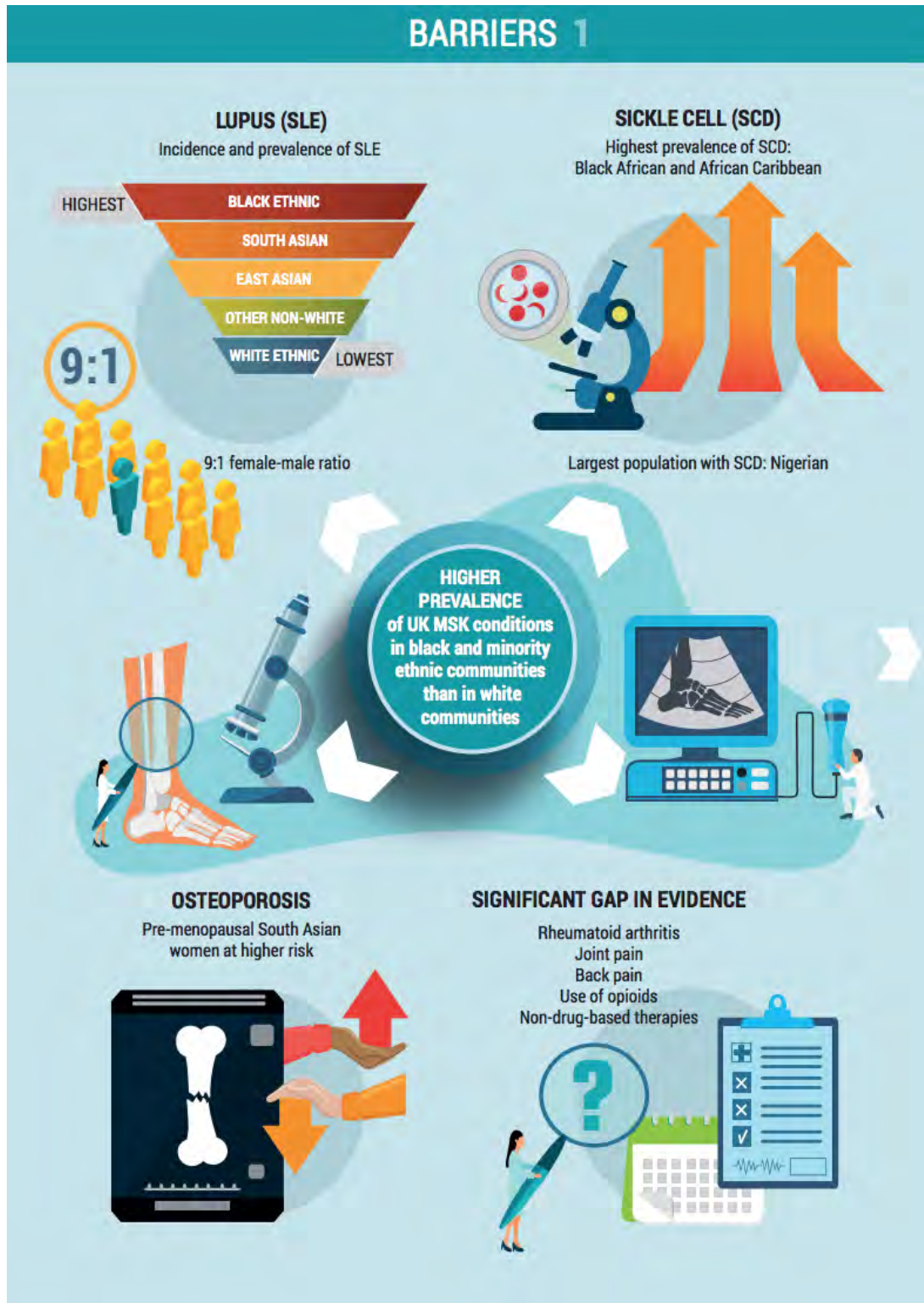
Summary

The focus groups and interviews highlighted the barriers to accessing care and inequalities in experiences including variable quality of information, and reliance on medication. They also underlined the importance of timely interventions, particularly those based on diet and exercise.

5 - Infographic

We summarised the findings of the focus group interviews into a series of infographics bringing together the literature review and qualitative findings.

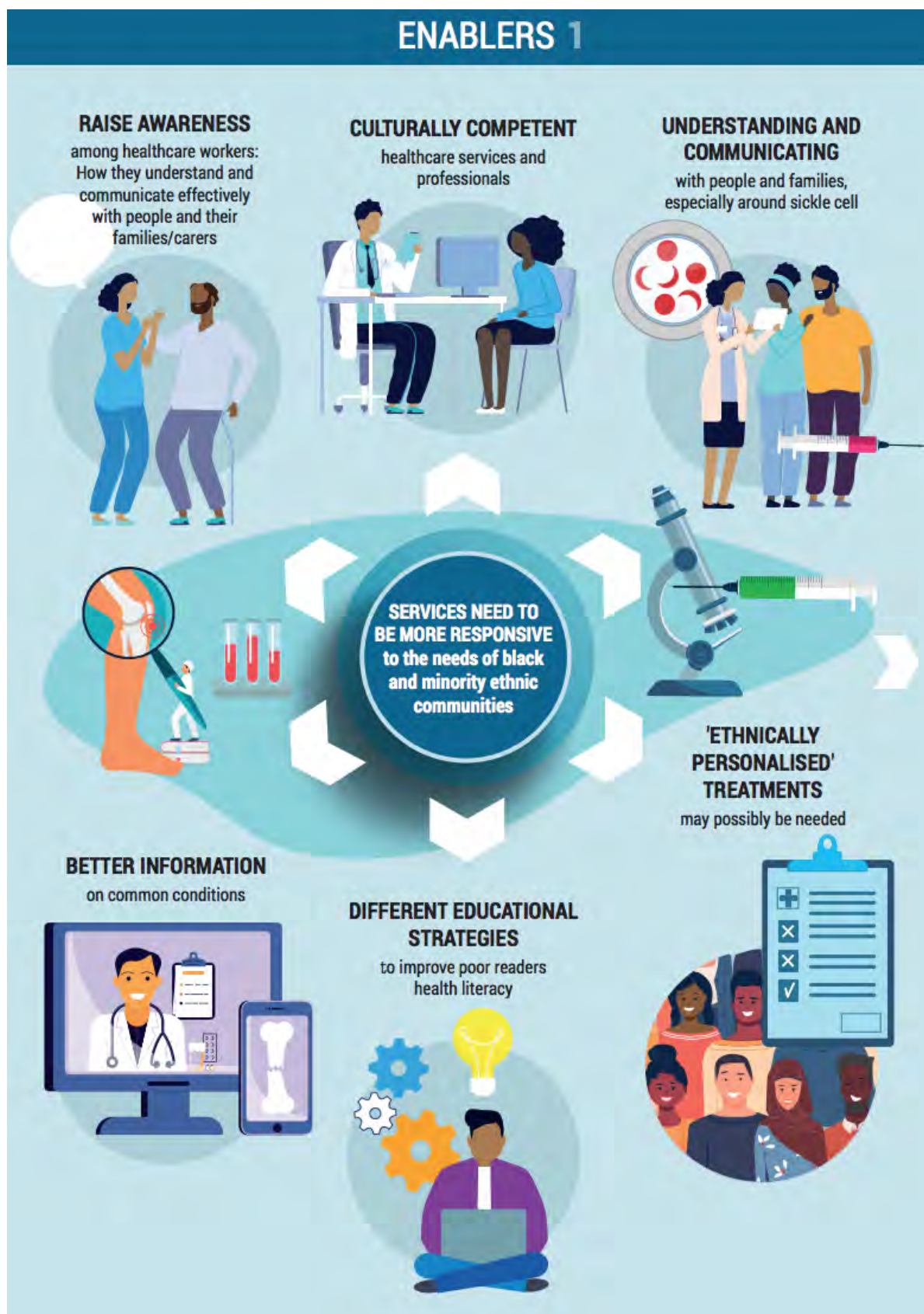
The first examines prevalence, specifically with regards to lupus, osteoporosis and sickle cell, while identifying the gaps with other common MSK conditions.



The second infographic examines the barriers and risk factors that contributed to poorer MSK health and poorer outcomes from services, including structural discrimination, socio-economic factors, attitudes to pain, and medication.



The third infographic looks at what can be done to improve those outcomes, including better awareness and communication, education, information and potentially ethnically personalised treatments.



The fourth and final infographic continues to look at enablers to better outcomes, including expanding and improving the quality of evidence going forward, support to bring in service providers and the voluntary sector and a focus on prevention.



6 - Carer case study

Many of these issues can be seen through two case studies we have included that show the journeys of a carer and a service user through services, particularly the importance of timely information and early intervention to prevent deteriorating health.

Sarah said her daughter was referred to the orthopaedic department for issues relating to sickle cell disease. “We just kept seeing them but they never really gave us any updates,” she said, adding that they never focused and this led to confusion. “We thought there was something going on, but they never talked to us about it,” she said. They were also receiving care from the rheumatoid arthritis team, who performed an MRI scan and that showed a possible lesion in her daughter’s knee cap.

Since then her daughter has had a sickle cell crisis. Sarah’s daughter had been able to walk into the hospital but by the time she was discharged her condition had deteriorated to the extent that she was unable to walk out, and has been unable to walk by herself since. According to Sarah, her daughter was unable to keep food, or medication for pain down but was refused fluids for a week. “They are now saying there’s nothing significant they can find and I’m just confused,” said the interviewee. “She has had to go off school and now has changed school after home schooling for a year.” She says her daughter has missed out on a lot in school and her social life and had lost touch with friends and become quite depressed. However, there has been relatively little support on these issues of isolation and subsequent low mood.

The interviewee said, “There were a few things I was unhappy with at the hospital. I lodged a complaint. It’s been a downhill spiral since then. The team implied it was just psychological that she couldn’t walk.” The interviewee didn’t feel that she had any control over her daughter’s care and felt ignored by the doctor. She got some advice from a friend with a similar condition to see private healthcare. “It took for her to not walk for things to be taken seriously. I raised these issues long before they became severe,” she added.

7 - Service User case study

David has scoliosis, which he was able to self-manage through regular exercise. This changed when he started a job that required him to stand up a lot in one position for 8 hours in customer service. He developed constant back pains and some pains in his feet from standing.

He later suffered a slipped disc and went to his GP for treatment. It was at the GP clinic that he requested an MRI scan. Meanwhile he was going to private chiropractor. He was “pretty impressed” with the waiting time for the MRI – it was within a couple of weeks. “I didn’t want to wait, so I went to the chiropractor at the same time,” he explained. “The chiropractor really helped me, because he looked at me from a holistic perspective – he prescribed some non-inflammatory diet changes. I really liked his alternative perspective looking at this issue and he really helped me,” he added.

Recently he injured his arm and got ‘arm infringement’ – some of the muscles around the joint got damaged and it took months to recover. This meant he could not do any exercise, which then triggered pain in his back and anxiety. He went to see a couple of people, but was not happy with the outcome. “Each doctor had completely different view of the issue. I spent a fortune and then I got an MRI and found out it was muscle damage. They requested physiotherapy for me, but I’ve been waiting for six weeks for an appointment date with them.,” he explained. “The GP didn’t tell me much about it. They didn’t really exactly know, ‘it might mean this or that.’ That really confused me and I was worried about doing the wrong thing and it taking longer. I researched things by myself and tried some different exercises – I use the internet as my source of help at the moment,” he added.

He feels the GP was helpful in getting the MRI scan, but not in taking it forward. He was given the option of steroid injections if the pain doesn’t go away, but that would not be recommended. “I feel like I have to suggest things to the GP and research them on my own. I feel it would be good to have a larger range of options,” he said.

If he could change anything it would be the waiting time for physiotherapy. This is because this issue stops him doing exercise, which causes spine pain, which triggers depression. A quicker response would be the answer. “It slows down your life”

8 - International examples of interventions

While we have yet to find any documented interventions in the UK supporting black and minority ethnic people with a musculoskeletal condition, there are several examples from other countries.

United States – The ACTION programme specifically targets African Americans with hip, back and knee pain. A counsellor calls them six times over a period of eight to ten weeks to provide coaching in order to get them walking regularly, the participants are also provided with a pedometer and information on exercise and their health (Bhimani et al, 2017). The aim is to both reduce pain and to improve physical functioning. The coaching and pedometer are intended both to overcome psychological and environmental barriers (for example, neighbourhoods that lack walking paths, poor access to parks, lack of time to exercise) and encourage behaviour change through plan-making, counselling and problem-solving. There is also specific mention of encouraging and supporting involvement of family and friends in planning. This type of coaching, mentoring and peer mentoring has been used in the UK in mental health (MIND, 2020), and it would seem very feasible to run a similar programme using peers or professionals.

Australia – A systematic review of pain management for Aboriginal Australians recommended: improving communication (including using visual aids), inclusive promotional information (both written and visual), and ensuring proper use of interpreters. The study also highlighted the importance of “decolonising” pain management, for example most of the clinicians administering injections are white and this was felt to implicitly reproduce the abusive racist power relationship experienced by Aboriginal Australians (Arthur, 2019). Pain Australia have [produced a resource](#) to show different ways to communicate information that reflects Aboriginal systems of knowledge. While the UK context is very different, there are undoubtedly lessons that could be learned from the reflection on the power relations in practice and ensuring effective communication. For example, Mind developed a publication with the help of Islamic scholars that enabled an exploration of mental health and psychology rooted in the rich history of Islamic psychology (Mind, 2020).

9 - Community of practice and options for the future

Throughout the project, the Foundation sought to build a 'community of practice', comprised of professionals, workers and service users. We presented at the Public Health England event on musculoskeletal conditions in January. We then organised our own specifically focused on the experience of black and minority ethnic people with an MSK condition. A total of 30 people attended the webinar, which heard presentations from the Foundation, University of Bedfordshire and Faith Action on our findings. Discussion focused on how people found interventions that worked for them, arthritis and the lack of specific evidence on the experience and prevalence, and the intersection with the pattern and type of work people do.

Unfortunately, a planned follow-up face to face event had to be cancelled due to the COVID-19 pandemic.

Our plan is to continue to build the conversation with the people who signed up and attended these events, initially through sharing the reports and evidence from this project. One of the ways we thought of encouraging members of the community of practice to initiate and take those conversations further was to develop a platform on Slack, an online communications hub, which would enable specific conversation to happen in sub-groups while maintaining a general multi-disciplinary and diverse membership.

10 - Conclusion and recommendations

As the UK's populations, including its black and minority ethnic populations continue to age (Truswell, 2013), the burden of MSK conditions will continue to grow. On top of this, black and minority ethnic people continue to be at greater risk of experiences that compound the risk of developing an MSK condition, such as poor housing and unemployment. Understanding how these affect communities in different ways allows us to better prevent, intervene at an early stage, improve outcomes and reduce inequalities.

There is a lack of robust research evidence that looks at MSK health and BAME communities in the UK. However, we would argue that action should not necessarily wait on improvements to the evidence base. Both the evidence base and inclusive practice can be developed together. This is particularly the case with common conditions, such as arthritis, which have significant research and service resources.

Recommendations by sector

NHS England, NHS Trusts, DHSC, PHE

- Professionals, workers, service users and carers, should be supported to develop conversations on what is currently working and not working, as well as providing insight and guidance for the development of new services and projects to address the inequalities highlighted here. The voluntary sector should play a key role in these conversations.
- Prevention should be given greater priority, and MSK health should be promoted with an emphasis on inclusive messaging and communication that will be understood and acted on by black and minority ethnic people and others experiencing inequalities.
- Service providers and Public Health England, Voluntary Sector NHS England and the Department of Health and Social Care must work together to improve the quality and availability of data to enable better analysis, including intersectional analysis. This could be added, for example, to the existing resource [available on Fingertips](#).
- Service providers should work with black and minority ethnic led organisations to adapt existing interventions and develop new interventions, particularly to improve access, experience, and the range of non-drug based treatments available. There are a wide range of models, particularly in mental health where there are similar issues

around medication, that voluntary sector organisations have developed to promote access and better outcomes such as peer mentoring.

The Voluntary and community sector

- Should develop a more specific offer around MSK conditions and those with them, including support to access exercise-based activities.
- Should seek a clearer picture of MSK needs in their communities.

Academics and research funders:

- Should invest in research that builds the evidence base on ethnicity and MSK conditions, including addressing inequalities, prevention and successful methods of promoting MSK health.

The need for intervention is clearly present, and while much can be done to improve the quality of evidence, there are established methods such as peer support that could quickly be mobilised to begin to address the MSK inequalities faced by black and minority ethnic people. In particular, improving access to exercise and diet-based therapies would have wider health benefits over the lifecourse.

11- Appendix: literature review search methodology

The search was conducted between September 2019 and January 2020 across five bibliographic databases: CINAHL, Medline, AMED, Global Health and British Nursing Database. The reference lists of papers selected as part of the main search and websites of interest were also hand searched for published reports on interventions/education programmes for improving the experience of healthy ageing for BAME groups in the UK. (Horsley, Dingwall and Sampson, 2011). These websites included [The National Institute for Health and Care Excellence](#).

The data bases mentioned above were searched for a combination of the following words and Boolean operators: Musculoskeletal AND (Ethnic groups OR Minority groups OR black OR Asian), (Arthritis OR Carpel tunnel syndrome OR Hip OR Knee OR Neck pain OR Low back pain OR Osteoporosis OR Sickle Cell OR Lupus) AND (Ethnic groups OR Minority groups OR black OR Asian). This search was supplemented by checking the reference lists of all literature which passed the screening stages. Using this criterion, titles, abstracts and where appropriate full-text screening was conducted. The choice of data bases and search terms was made in consultation with an experienced subject librarian (DA).

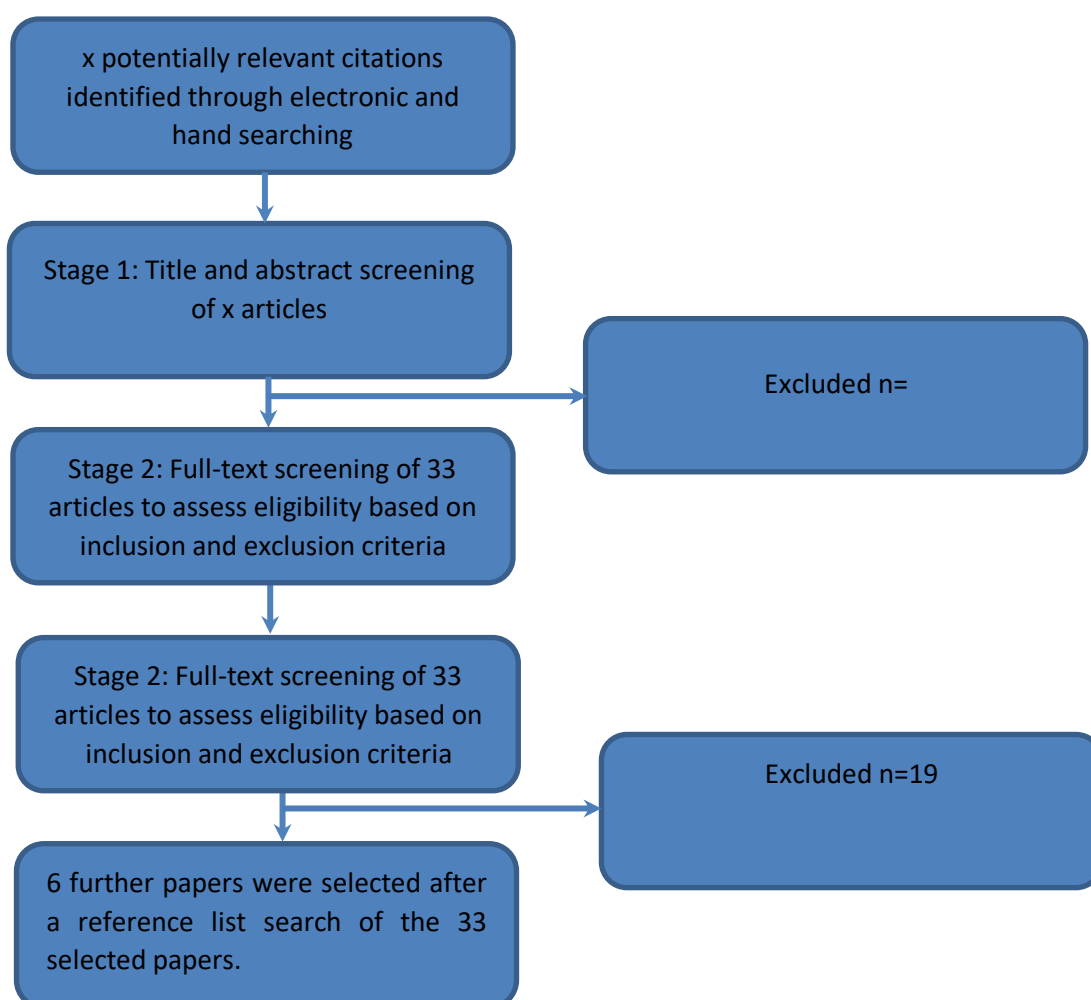
Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Primary and secondary empirical studies. Quantitative, qualitative and mixed methods Systematic reviews and conceptual/theoretical papers	Papers reporting clinical trials
Peer reviewed journal articles, books chapters, or reports	Non peer reviewed journals Newspaper/media articles. Literature not published in peer-reviewed journal articles, reports or book chapters, grey literature, secondary literature
Published in English Language	Articles published in all other languages
Published between January 1990 and January 2020 were included.	Published before January 1990
If related to prevalence of musculoskeletal conditions. If discussing barriers and enablers If reporting interventions/education programmes for improving the experience of healthy ageing for BAME groups in the UK	Related to clinical trials If not related to barriers and enablers If not reporting interventions/education programmes for improving the experience of healthy ageing for BAME groups in the UK

Screening

Figure 1 below shows the Prisma flow diagram of the study showing the selected articles are presented below. Duplicated papers were removed and the titles and abstracts of the remaining 33 papers were read by NA and DA. IQ provided a second opinion. 6 further papers were selected after a reference list search of the 33 selected papers. The main themes related to the aim of the literature review are presented in section 3.0 below.

Figure 1 Prisma Flow Diagram



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