

Written evidence submitted by Versus Arthritis (CLL0067)

1. Versus Arthritis welcomes the opportunity to respond to the Health & Social Care Committee and Science & Technology Committee joint inquiry on 'Coronavirus: lessons learnt.'¹
2. Versus Arthritis is the charity formed by Arthritis Research UK and Arthritis Care joining together. We work alongside volunteers, healthcare professionals, researchers, and friends to do everything we can to push back against arthritis. Together, we develop breakthrough treatments, campaign for arthritis to be a priority and provide support. Our remit covers all musculoskeletal conditions which affect the joints, bones and muscles including osteoarthritis, rheumatoid arthritis, back pain, and osteoporosis.²
3. Arthritis and related musculoskeletal conditions affect 18.8 million people in the UK and are the single biggest cause of pain and disability in the UK. Cumulatively, the healthcare costs of osteoarthritis and rheumatoid arthritis will reach £118.6 billion over the next decade.³ Musculoskeletal conditions account for a fifth of all sickness absence and result in the loss of around 28.2 million working days to the UK economy each year.⁴
4. This submission responds to two specific topic areas raised by the Committees as part of the inquiry:
 - The deployment of non-pharmaceutical interventions like lockdown and social distancing rules to manage the pandemic.
 - Government communications and public health messaging.
5. We have also submitted evidence to government bodies, APPGs, and previous select committee inquiries on the impact of COVID-19 during 2020 including:
 - Public Health England (PHE) request for evidence on the impact of COVID-19 people with arthritis, and on mitigation measures in April.⁵
 - The Health & Social Care Committee Inquiry on 'Delivering Core NHS and Care Services during the Pandemic and Beyond' in May.⁶
 - The opportunity to contribute views to our National Clinical Director and NHS England on the impact of COVID-19 on people with musculoskeletal conditions throughout the year.
 - The Department of Health and Social Care's work on the impacts of COVID-19 shielding in June.
 - Scottish Government's request for information on impacts of COVID-19 shielding on people with arthritis in June.⁷
 - The House of Commons Sciences and Technology Committee Inquiry into the role of technology, research, and innovation in the COVID-19 recovery in September.⁸
 - Written and verbal evidence to the APPG on Coronavirus Inquiry on 'UK's handling of the coronavirus outbreak' in October.⁹

[The deployment of non-pharmaceutical interventions to manage the pandemic](#)

6. In order to better understand the impact of COVID-19 and the subsequent restrictions on people with musculoskeletal conditions, Versus Arthritis carried out survey research in July 2020, exploring the ongoing experiences of over 1000 people with musculoskeletal conditions during the pandemic.¹⁰

Physical and mental health

7. Our research found that COVID-19 and the subsequent restrictions have made it more challenging for people with musculoskeletal conditions to maintain their health, with 1 in 3 (32%) of people surveyed reporting that COVID-19 has made it harder for them to manage their condition. Additionally:¹⁰
 - 53% reported their mental health was worse
 - 45% said their pain had become worse
 - 45% reported more issues with their mobility.
8. Analysis of queries across all our channels, including our helpline, social media, e-mail and other public-facing interfaces showed that in the weeks following the implementation of the national lockdown measures in late March, there was a 200% increase in pain-related queries over the previous three-month average.
9. This reported deterioration in both physical and mental health for individuals with musculoskeletal problems can be attributed to a number of causes, including:
 - **Interruption in routine care** – Our survey research showed that people have had to cope with the widespread disruption in routine care due to COVID-19, according to our respondents:¹⁰
 - 60% of physiotherapy or podiatry appointments had been cancelled and a further 28% had been rescheduled or moved to online/telephone only
 - 72% of treatment sessions to manage pain or improve mobility had been cancelled, with all other appointments being delayed or moved online.
 - 75% of exercise classes had been cancelled and an additional 12% had been rescheduled or were now being run virtually.
 - Of those who received virtual appointments during COVID-19, 44% of respondents said they were worse than the previous face-to face care they received.¹⁰
 - **Cancellation of elective surgeries** – Due to COVID-19, all elective care was suspended for 3 months, and elective surgery activity levels still have not returned to pre-pandemic levels in most areas of England.¹¹ Extended waiting times and ongoing uncertainty have a serious negative impact on the physical health and mental wellbeing of people waiting for joint replacement surgery.
 - **Reduction in physical activity** – Exercise is a vital part of many people with arthritis' approach to managing their musculoskeletal pain. A range of factors including; the closure of leisure centres, suspension of exercise groups, shielding restrictions, not feeling comfortable using outdoor exercise spaces because of concerns around catching COVID-19, and not having appropriate space or resources to exercise at home, have all acted as barriers to people's ability to stay physically active, and in turn have made it harder to maintain their musculoskeletal health.

Loneliness, isolation and shielding

10. Increasing isolation has also been a major concern during the pandemic for those living with musculoskeletal pain, in part because struggling with loneliness and social withdrawal were already reported as common problems for those with musculoskeletal conditions. Even before the pandemic, survey research for our 2018 report 'Defying Arthritis at every age' found 76% of people with musculoskeletal conditions felt their condition compromised their relationship with family or their social life, and 41% of young people with arthritis (16-34 years old) regularly felt lonely.¹²
11. This epidemic of isolation has been exacerbated by the pandemic. Initial feedback from a survey of the Versus Arthritis community, which had over 6,000 responses and ran from April to June 2020, found that 45% of respondents felt lonelier and more isolated due to COVID-19.¹³
12. With regards to the impact of shielding on people with musculoskeletal conditions, our July survey of over 1000 people with musculoskeletal conditions indicated that 4 in 10 (43%) respondents shielded at some point in the first wave of the COVID-19 pandemic, but only a quarter of respondents received an official shielding letter. Almost half of those surveyed had made an active decision to shield themselves, outside of the official advice.¹⁰
13. This dynamic speaks to the level of concern, anxiety, and confusion among vulnerable groups about how best they could keep themselves safe during the initial wave of COVID-19. It is also important to note that some individuals have continued shielding throughout the pandemic.
14. Shielding was a challenging experience for individuals with musculoskeletal conditions, and almost a third reported that they decided to stop shielding, for a number of reasons:¹⁰
 - 33% stopped due to a need for greater physical activity
 - 27% stopped because they needed greater social interaction
 - 25% stopped because they lacked support for getting vital supplies including food and medicines.

Insights in the second wave

15. Our recent insights also illustrate that people's concerns have continued into the second wave of COVID-19, and the reintroduction of national level restrictions. In October 2020, we conducted survey research of our campaigner network and collated the responses from over 1,500 people with musculoskeletal conditions about their concerns around the impact of a second wave. This survey of people with musculoskeletal conditions found that:¹⁴
 - 59% of respondents were more concerned than they were at the beginning of the pandemic in Spring.
 - 66% of all respondents said they were concerned about their ability to access non-COVID health services.
 - On physical health, mobility and staying active:

- 74% of respondents reported that they were worried about the impact of the pandemic on their physical health and managing their pain
- 69% said they were worried about the impact on their mobility and staying active
- 31% of respondents were most concerned about accessing leisure facilities including gyms and swimming pools.
- On mental health and wellbeing:
 - 68% of respondents said that they were most concerned about not being able to see their friends and family
 - 58% were worried about the impact of the pandemic on their mental health.
- For individuals who were shielding during October:
 - 37% of respondents indicated that they were shielding as part of the second round of national restrictions
 - 42% of respondents who were shielding said that they had not received an official instruction to shield but felt they needed to shield anyway
 - 54% of people who were shielding were concerned about communication and support for the clinically extremely vulnerable
 - 40% of people who were shielding were concerned about their access to medicine, shopping, and other essentials.

The development of new musculoskeletal problems

16. The COVID-19 pandemic has also created new and unexpected challenges for the general public in maintaining their musculoskeletal health. An interim report from the Institute of Employment Studies found a significant increase in musculoskeletal pain among home workers, with more than half of the survey respondents reporting new aches and pains compared to their normal physical condition (including a 55% increase in back pain, a 58% increase in neck pain, and a 49% increase in knee pain).¹⁵ Furthermore, a third of respondents reported eating a less healthy diet and 60% were exercising less.¹⁵ Poor sleep, fatigue, and mental health concerns were also widespread, and are all associated with increased musculoskeletal pain.¹⁵ The requirement to work from home wherever possible, often without ergonomic office equipment, is thought to be the central driver for the predicted increase in musculoskeletal pain.¹⁶

Calls for action:

17. **Given the outsized impact that non-pharmaceutical interventions like 'lockdown' and shielding restrictions have had on individuals with musculoskeletal problems, their health and wellbeing must be considered and supported in future waves of the pandemic where additional restrictions may be required.**
18. **To help people with musculoskeletal conditions whose health has been negatively affected by the impact restrictions have had on routine in-person care:**
 - **NHS England should fund and promote online and digital self-management support tools and services, including those provided by charities such as Versus Arthritis home exercise programme 'Let's move with Leon'.¹⁷**

- **Local authorities should ensure local data collection on the incidence of COVID and the ongoing impacts on the health status and outcomes of people with musculoskeletal conditions, and include such data in their COVID-19 recovery plans.**
19. **To address challenges faced by people facing increased waiting times for joint replacement surgeries:**
 - **Local providers should implement the National Institute for Health and Care Excellence’s recommendation for pre-operative rehabilitation for people waiting for joint replacement, and ensure that service provision is co-developed with input from people with musculoskeletal conditions.**
 - **NHS leaders need to work with local systems and private providers to ensure that elective surgery continues as much as is possible, and is only suspended if absolutely necessary.**
 20. **The government needs to provide greater support to people with musculoskeletal conditions to stay physically active in a wide range of settings, so that individuals can continue to exercise under whatever restrictions are in place.**
 21. **Specific resources should be developed to encourage people who are considered to be Clinically Extremely Vulnerable (CEV) to be physically active in a range of settings.**
 22. **Local authorities should also develop strategies to encourage CEV people to exercise within their own homes, with signposting to resources like Versus Arthritis’ ‘Let’s Move with Leon’ programme.¹⁷**
 23. **Local Authorities (working with leisure operators) should consider introducing dedicated time slots, additional precautions (i.e. deep cleaning and increased social distancing) and concessionary pricing for CEV people to use their facilities. This could be delivered in line with the new partnership between UKActive, NHS England, Sport England, and the National Academy for Social Prescribing, which aims to support people in managing their health through the social prescribing of fitness and leisure activities.¹⁸**
 24. **People in vulnerable groups, including those with diagnosed musculoskeletal problems, need to be proactively directed towards the mental health and wellbeing support options that are available to them, including self-management tools, community forums and online resources.**
 25. **Any new instructions to shield should be minimised and targeted with a more clearly defined threshold and time limit, drawing on learnings from the first wave. All possible alternatives should be explored before an instruction is given to CEV people to shield again.**

Government communications and public health messaging

General communication during the pandemic

26. Our survey research conducted in July about the impact of the pandemic on people with musculoskeletal conditions also explored the perception of the government's advice about COVID-19 and shielding and found:¹⁰
- 46% did not think the UK government's guidance was clear
 - 55% were confused about the differences in advice between the four nations
 - 54% were not sure whether the government shielding guidance applied to them or not.
27. The results also highlighted how significantly people with musculoskeletal conditions' trust in the guidance varied depending on the source they received it from:¹⁰
- 86% of people trusted the guidance given by healthcare professionals
 - 82% trusted advice from local NHS health services
 - 48% of respondents said they trusted the UK government's advice
 - 47% trusted the advice on their local council website.
28. The confusion around government guidance and how it applied to people with musculoskeletal conditions was also made clear through our public support channels, which experienced an influx of COVID-19 related questions during the initial lockdown. The overwhelming volume of queries we received prompted Versus Arthritis to create COVA, a COVID-19 Virtual Assistant chatbot that was designed to answer people's COVID-specific questions throughout the pandemic.

Communication about planned (elective) care, including joint replacement

29. As previously mentioned, all types of routine treatment for musculoskeletal conditions have been interrupted in some way by COVID-19. This is especially true for joint replacement surgeries, as 75% of respondents in July reported that their surgery had been cancelled or rescheduled.¹⁰
30. As part of our [Impossible to Ignore](#) campaign, we've been collating the experiences of people who are waiting for joint replacement surgeries during the pandemic. Many of those affected by these cancellations report feeling abandoned or forgotten by the health system, due to a lack of clarity and consistent communication about their treatment.
31. Over October and November, we ran a survey of individuals with musculoskeletal conditions who are currently waiting for joint replacement surgery across the UK, which included the experiences of 861 respondents. That survey found:¹⁹
- Only 13% of those waiting for an operation had been given a likely surgery date or estimated waiting time
 - 53% of respondents had an operation or appointment cancelled or postponed by their hospital during the pandemic
 - Of those whose appointments or surgeries had been cancelled or postponed, 75% had not received a new date for their operation or appointment.

32. There is significant regional variation in the level and detail of information and support people on these waiting lists are receiving, and many are unaware of who they should contact if they have any questions or if their condition deteriorates substantially.
33. The lack of communication about their treatment has been a considerable cause of anxiety and stress for those affected, in addition to the mental health impact of living with chronic pain in the context of a pandemic.

Calls for action:

34. **Government advice and public health messaging around COVID-19, including shielding guidance, should use the language of risk management and mitigation to help empower vulnerable groups to follow the guidance in a way that is sustainable, and does the minimum amount of damage to their mental and physical health.**
35. **Broader government guidance needs to articulate the level of risk based on your health status: clinically extremely vulnerable (CEV), extremely vulnerable (EV), living with multiple long-term conditions (MLTCs), living with one long-term condition. The development of a risk-stratification tool designed to help people understand their own vulnerability to COVID-19 in a more tailored way would be beneficial.**
36. **The guidance and messaging for the public needs to be coordinated and consistent across all national, devolved, regional government channels, local council communications, and NHS platforms and services, to ensure people are not hearing contradictory information from different sources.**
37. **Local authorities, patient groups and professional bodies should be consulted with a proper notice period on any changes to guidance affecting vulnerable groups, including CEV individuals. Patient charities and organisations can act as strong channels for two-way communication between the government and the communities they represent.**
38. **The government should put out clear communications outlining which individuals are required to shield, and the reasoning behind any changes to the shielding lists, to minimise the number of people shielding unnecessarily.**
39. **Written communication with CEV people should include information about keeping physically active and the benefits of doing so, and signpost them to relevant online and local resources which can support them to exercise while shielding.**
40. **To support individuals who are now facing a protracted and indeterminate wait for joint replacement surgeries, the NHS should implement a minimum standard of communication, which all patients on waiting lists should receive from their Trusts.**
41. **The minimum standard should:**

- **Provide a single point of contact through a method which works best for the patient, so they know who to contact with questions, or in the event that their condition significantly worsens.**
- **Enable clear shared decision-making, mechanisms for the patient to provide a response, and ensure patients are given enough information to facilitate an informed discussion about their treatment.**
- **Clearly set out what patients can expect when accessing care (e.g. protocols for mask wearing, being accompanied to appointments) so they can plan accordingly.**
- **Inform the patient when they can expect further communication from Trusts about their care, either after a set amount of time has passed or whenever there is an update in what care is available.**
- **Signpost to alternative and credible channels for information e.g. health charities and/or other local support as well as alternative services to help manage their condition where appropriate.**

For further information on this submission, please contact: Madeleine Webb, Policy Officer, Versus Arthritis

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