

## MSK Lived Experience Themes of What Matters

COVID-19 has provided an opportunity to re-evaluate our MSK services and develop them for the future. It is important these developments are properly informed by patient views and co-produced with patients.

In March 2020 the UK experienced lockdown in response to the COVID-19 pandemic. Lockdown affected everyone in different ways and in May-June 2020 a range of surveys were undertaken with MSK patients to understand their experiences. This included an understanding of their thoughts and feelings on how they would like to see things move forward whilst in lockdown and into the 'new normal'. Thoughts from people living with MSK conditions were gathered from Versus Arthritis, ARMA, the Royal Osteoporosis Society and from a range of individuals. This information was collected from online surveys, helpline calls, social media, phone or video-conferencing calls, patient advisory groups and patient led groups.

The information collected was compiled by the Lived Experience Group (LEG), who are informing the National MSK Restoration Plan. The aim was to ensure that we found out what mattered to MSK patients and that this informs the MSK Restoration Plan. We hope local/regional MSK services will undertake similar rapid reviews to inform local/regional MSK services to look like going forward.

Sketch note which visually outlines what matters to people using MSK services and clinicians:



The following table summarises the 12 themes identified as what matters by people living with musculoskeletal conditions:

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Access to clear and accurate information	Access to Treatment and Care
<ul style="list-style-type: none"> <li>• Shielding and medication: need for a helpline with access to clear and consistent information– particularly for those with complex conditions and the vulnerable.</li> <li>• Confusing information led some people to shield and/or stop working unnecessarily.</li> <li>• Lack of guidance on changing treatment/medication to reduce vulnerability.</li> <li>• Need for guidance distinguishing reliable from false information.</li> <li>• Need for clear guidance to over 70s particularly.</li> </ul>	<ul style="list-style-type: none"> <li>• Telephone consultations – positive but should not replace face to face completely. Not having to travel an advantage with virtual consultations.</li> <li>• Patients should be able to choose whether their remote consultation is undertaken on phone or video.</li> <li>• Mixed experience getting blood and other tests (to accompany consultations).</li> <li>• Inconsistency between and within regions/services; some treatments cancelled; others switched to virtual; appears arbitrary.</li> <li>• Cancellation of operations a major source of anxiety and uncertainty.</li> <li>• Poor access to treatment and advice affects the ability of patients to manage their conditions, especially new patients.</li> <li>• Some osteoporosis patients reported cancellation of ongoing injections, which cannot be safely stopped without alternative. If stopped there was an inability to get advice about side-effects.</li> <li>• Lack of communication from NHS about cancelled treatment leaves patients feeling anxious, abandoned and with no one to talk to about their concerns.</li> <li>• Need for consistent, safe use of PPE by staff in hospitals for patient safety and reassurance.</li> </ul>
Mental Health – Well-being	Diet and Exercise – General Health
<ul style="list-style-type: none"> <li>• Increasing despondency, helplessness anxiety and depression.</li> <li>• Isolation and loss of social contact increases anxiety for many; switch to online inspires some people to greater than normal social engagement/activity.</li> <li>• Anxiety on behalf of friends and family working in high risk environments.</li> <li>• Anxiety about going outside/using public transport, especially if social distancing flouted.</li> <li>• People with chronic conditions who had returned to work feel set back by crisis.</li> <li>• Anxiety due to cancellation of medical treatment.</li> <li>• Intervention: need for integrated physical-mental health-well-being care; more publicity about talking-support services;</li> </ul>	<ul style="list-style-type: none"> <li>• Concern about potential weight gain during lockdown due to loss of normal exercise groups and facilities, e.g. pool-based exercise classes. Exercise groups also good for mental health.</li> <li>• Shielding osteoporosis patients have difficulty getting calcium rich diet and exercise.</li> <li>• Adults with learning difficulties hit hard during lockdown by disruption to activity/exercise.</li> <li>• Some people have found it easier to regulate exercise during lockdown.</li> <li>• Food deliveries: shortage of slots initially limits access; not all those shielding are on lists sent to supermarkets; government deliveries not catering for special diets.</li> <li>• Online exercise and cooking resources very useful for some people.</li> </ul>

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<p>online exercise classes can provide opportunity to socialise.</p>	
<p><b>Pain and Symptoms</b></p> <ul style="list-style-type: none"> <li>• Many pain services have stopped, leaving patients (e.g. with osteoporosis) to self-manage.</li> <li>• Need for online services to be established rapidly to prevent; delays in support, patient's conditions deteriorating, waiting lists expanding (which increases delays and anxiety).</li> <li>• Patients experience increasing pain due to loss of activity, support and distraction. Some find they can adapt their self-management to new conditions and improve their 'pacing'.</li> <li>• Online pain management resources could help, e.g. mskr.info website set up by physios.</li> </ul>	<p><b>Peer Support and Self-management</b></p> <ul style="list-style-type: none"> <li>• Need to ensure that no one who needs support gets forgotten or neglected, and that person-centred holistic care is provided.</li> <li>• 'Rehabilitation' services supporting a range of comorbidities could be community-based.</li> <li>• Camden and Islington NHS Trust's Control and Choice Programme uses peer mental health coaches.</li> <li>• NHS support groups could be resumed online.</li> <li>• Need to work alongside charities, community groups and volunteers.</li> <li>• Self-help support groups could network to spread support more widely.</li> </ul>
<p><b>COVID-19 specific themes</b></p> <ul style="list-style-type: none"> <li>• Special challenges for those with multiple morbidities (telephone support needed).</li> <li>• Osteoporosis patients have issues; anxiety attending GP or outpatients, confusion about shielding and contact during treatment, fear that a Covid cough could break bones.</li> <li>• Anxiety and confusion about vulnerability of BAME community.</li> <li>• Problems for those in supported living: PPE shortages for staff; agency staff not used due to risk of infection; visits to A&amp;E can result in overnight stay which then requires quarantine.</li> <li>• Concerns about competence of private firms handling PPE, testing and care workers' safety.</li> <li>• The ability to discuss the latest government advice about COVID with your clinician in order to understand how it applies to you</li> </ul>	<p><b>Shielding</b></p> <ul style="list-style-type: none"> <li>• Lack of clear, consistent advice on shielding leads to confusion and anxiety, especially in households with several people with same health condition.</li> <li>• Patients told to self-identify for shielding but criteria unclear in generic government letter.</li> <li>• Problems providing employers with proof of shielding status.</li> <li>• Easier to shield (e.g. with asthma) when living with non-shielded partner who can shop.</li> <li>• Public discourse around ending lockdown leaves shielding patients feeling ignored.</li> </ul>
<p><b>Advice on risk</b></p> <ul style="list-style-type: none"> <li>• COVID related terminology confusing to some patients.</li> <li>• Lack of clarity from government about risk to certain groups of patients: those at high risk due to their condition or medication (e.g. arthritis); children.</li> </ul>	<p><b>Employment, Volunteering and Benefits</b></p> <ul style="list-style-type: none"> <li>• Shielding problems: people uncertain about their shielding status keep working despite risk; difficult for employees asked to return to work when they live with people shielding; shielded workers put on SSP not furloughed despite government advice.</li> </ul>

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<ul style="list-style-type: none"> <li>Lack of clear advice increases anxiety which worsen symptoms (e.g. for pain patients).</li> </ul>	<ul style="list-style-type: none"> <li>Financial support for those unable/unwilling to go back to work – is this available?</li> <li>Volunteering – potential benefits problems?</li> <li>Time specific research grants – anxiety about these running out during crisis.</li> <li>Employers’ duty of care to employees returning to work – uncertainty about this.</li> <li>Homeworking: works well for some people, better than in workplace.</li> </ul>
<p><b>Technology</b></p>	<p><b>Access to Services, Supplies, Social Care</b></p>
<ul style="list-style-type: none"> <li>Online consultations often well received: fast, in-depth appointments; video consultations allow physios to calibrate exercises to patient’s home; patient can move around or switch off camera and lie down; don’t have to travel to clinic; support groups with patients, clinicians, administrators can be run.</li> <li>Online resources: a multitude of these have sprung up including yoga, meditation, exercise.</li> <li>Problems: some patients (e.g. with arthritis) struggle to access online conferencing platforms; Attend Anywhere has proved difficult to use with groups; privacy can be an issue in online consultations for those who live with others.</li> <li>Confidentiality issues</li> </ul>	<ul style="list-style-type: none"> <li>Difficulty getting shopping slots for people who are shielding</li> <li>Long queues at shops difficult people with pain or disability.</li> <li>Loss of support such as cleaner for those who rely on this help.</li> <li>Too much bureaucracy impedes access to social care.</li> </ul>

We are looking to do further work to understand the current experiences of MSK patients and what matters to them during the latter months of 2020.