**The difference made to the NHS England Musculoskeletal Services (MSK) programme by the Musculoskeletal Lived Experience Group (MSK LEG), NHS England and Improvement** **#BestMSKHealth Collaborative**

Written by Mark Agathangelou and Christine Price, Lived Experience Partners, MSK LEG

**Synopsis**

In June 2020 the Musculoskeletal Services(MSK) Recovery Group was established with a complement of lived experience partners and stakeholders from MSK groups, alongside healthcare professionals. The intention was to work together collaboratively to assist with restoring and improving MSK services in the wake of the COVID pandemic lockdowns.

This group evolved from its hastily assembled early iteration into a well-formed and diverse Musculoskeletal Lived Experience Group (MSK LEG). Each member of the new MSK LEG has experience of a relevant MSK condition and were rigorously interviewed and appointed after an open and accessible selection process.

MSK LEG have already co-produced its own terms of reference and engaged in providing feedback on various MSK pieces of work. The group have helped shape the evolution of the #BestMSKHealth Collaborativeprogramme and some members have presented alongside the National Clinical Director and various MSK clinicians to a range of audiences at events. The group has also been used as an exemplar of co-production within the NHS.

As part of their work, MSK LEG members are assigned to nine national MSK workstreams, providing feedback, co-designing work and engaging in true coproduction. Members work both individually and collectively as a team. MSK LEG continues to evolve and develop a strong sense of identity and teamwork.

The MSK LEG team has been developed from strong principles of co-production and has already made a difference to the recovery and advancement of MSK services throughout the UK.

**Key contacts**

MSK Leg Lived Experience Partners:

**Mark Agathanelou** - [mark.agathangelou@nhs.net](mailto:mark.agathangelou@nhs.net) and

**Christine Price** - [christine@cprice.me.uk](mailto:christine@cprice.me.uk)

Co-production Programme, Experience of Care Team, NHS England and Improvement:

**Cristina Serrão** Lived Experience Ambassador - [cristina.serrao@nhs.net](mailto:cristina.serrao@nhs.net) and

**Helen Lee** Experience of Care Professional Lead - Co-production, [helen.lee12@nhs.net](mailto:helen.lee12@nhs.net)

**Background**

MSK difficulties affect a large part of the population and have a big impact on quality of life and ability to work. They are perhaps the leading cause of disability in England. Historically MSK services were developed by clinicians and academics alone. There was very little co-design or co-production involved, resulting in services that were sometimes arguably more geared to the clinicians needs than the people using the services and their carers.

**The need**

The first long COVID-19 pandemic lockdown, starting in March 2020, had a devastating effect on the provision of MSK services. For a while face to face consultations became a rarity and telephone and video consultations became common place. MSK clinicians had to quickly learn new skills to assess and treat patients in these unfamiliar formats. The number of patients treated by MSK clinicians was significantly reduced as therapists were re-deployed to care for COVID patients. Almost overnight the landscape of MSK services changed out of all recognition.

It was quickly clear that going forward MSK services would need to be remodelled, not only to cope with pandemic times, but also to move into the future. Although the pandemic created challenges, it also created opportunities for new and better MSK services.

Opinion was strong amongst both people using services and clinicians that services should not just be put back to how they were pre-pandemic but should embrace the many innovations adopted during the crisis, including the widespread use of video consultations. Many people using services, and clinicians, preferred the new ways of working. It was evident that people wanted to be provided with more choice as to how MSK services are delivered to them.

For such large-scale re-modelling to be successful it was evident that all stakeholders would need to play a part in the development process. It was recognised that clinicians re-modelling existing services and designing new ones on their own could easily result in services that people didn’t want or were not sufficiently accessible to them. It was evidently important to seek the views and experience of all MSK stakeholders including, perhaps most importantly, people using the services and their carers to get the best possible MSK services for the future.

**The solution**

In rapid response to the first COVID-19 lockdown a MSK Recovery Group was set up in June 2020. This comprised a small group of lived experience partners and other stakeholders such as [ARMA](http://arma.uk.net/), [Versus Arthritis](https://www.versusarthritis.org/), clinicians and policy leads. Its purpose was to provide input into the shaping of national strategy and policy. Regular meetings were held with the National Clinical Director of Musculoskeletal Services, Andrew Bennett.

Due to the immediate need for this group, arising from the unexpected national pandemic lockdown, which was having a devastating impact on MSK services, an initial relevant lived experience partner cohort was brought together.

Lived experience members of the group were aware that when the time was right the group would need to be re-formed, and an equitable appointment process followed.

This re-forming process took place in September 2021, and the current MSK Lived Experience Group (MSK LEG) was born. This new iteration of the group was created through a nationally advertised, rigorous, open selection procedure, taking full account of ensuring accessibility and diversity. The original members were given equal opportunity to apply and went through the same recruitment process. They were interviewed and appointed to the new MSK LEG, and they were joined by a number of new lived experience partners. The MSK LEG is diverse in terms of protected characteristics, skills, and experience.

The original MSK Recovery Group was created with the intention of providing lived experience input to the work of senior healthcare professionals developing new policy and mapping a way forward for MSK services. A genuine co-production environment was created and there was a strong sense that lived experience partner involvement was truly valued and promoted by leadership. The group co-produced its own terms of reference and ways of working. Various pieces of work were brought to the group for their analysis and input. Importantly, the group had an impact on the formation of MSK policy by providing a detailed analysis of what matters to people using services, and appropriate challenge and support. The lived experience partners brought insight additional to their own from their already established networks and community groups.

The functioning of the new, re-formed, MSK LEG is twofold. A lived experience partner, with specific relevant lived experience, has been assigned to each of the nine MSK Workstreams to support specific MSK developments. The MSK workstreams currently are: Orthopaedics, Spinal, Paediatrics, Osteoporosis Falls and Fragility, Fractures, Rheumatology, Data, Urgent and Emergency Care, Supported Self-Management, Diagnostics and Primary and Community Care. In addition, MSK LEG members come together to discuss both general issues and some specific areas of focus. They provide group feedback on particular issues brought to them from either the individual MSK workstreams, or elsewhere.

Although their involvement in the MSK workstream system has not been in place long, already many MSK LEG members have made an impact on their decision-making processes. For example, in the Primary and Community workstream the new Pathways Toolkit has been co-designed with a MSK LEG lived experience partner, who has also helped shape thinking on metrics and leaflets. The MSK LEG as a collective is currently co-producing a new Patient Initiated Follow Up (PIFU) infographic with the Primary and Community team. These are only examples of the extensive work undertaken.

**Costs**

Understanding the full cost implications is beyond our remit but obviously the Experience of Care team have provided a lot of time to this project, as have #BestMSKHealth Collaborative

There is a direct cost in terms of LEG lived experience partners being paid as Patient and Public Voice (PPV) role 4 for attending meetings and engaging with pieces of work as per NHS England Improvement policy.

**Challenges**

The initial MSK Recovery Group was created as a response to a major challenge, that of the pandemic. The initial group lacked diversity and was arguably inequitable in opportunity. The pandemic created logistic challenges, for example it was necessary for the group to meet online exclusively, something generally regarded as suboptimal pre-pandemic in terms of group cohesion and networking. It is generally accepted that regular online / virtual meetings can be very tiring, hard to focus on and they of course raise issues around digital exclusion.

However, every cloud has a silver lining and online meetings did enable people who might otherwise not have been able to participate to be involved. Accessibility in a sense has been increased as it’s relatively easy to organise meetings that bring people together from across the country.

When the MSK Recovery Group was put together there wasn’t a ready-made template of how to operate, and much work had to be done to develop thinking, policies, and ways of working. There was also a great deal of uncertainty for members, as it was unclear how long the group would continue and in what form. The MSK Recovery Group faced many challenges, and not only survived but evolved into a group that has made a powerful and important impact on the redevelopment of future MSK services.

**Impact**

Both the MSK LEG and its predecessor the MSK Recovery Group have positively supported the development of the #BestMSKHealth Collaborative programme. Members have provided insight, support and challenge. This has not only been through discussions with strategic leaders in meetings, but also through the co-production of the document ‘Lived Experience Themes of What Matters’. This document reflected the views of a variety of stakeholders and people with lived experience and considered their experience of MSK services during lockdown, and how they would like services to be redeveloped post-lockdown.

We have provided insight and feedback into many individual pieces of MSK work, acting as valued team members and bringing ‘what matters’ to people using MSK services to the heart of the programme.

Through sound leadership of the group, good relationships within the group, and a collective enthusiasm to work in a co-productive way, we have been able to develop a model of co-production working that has been used as an exemplar for other projects and teams throughout the UK. For example, we have showcased our co-production model through presentations at the National Orthopaedic Alliance conference and in a blog co-created with ARMA.

**Lessons**

Throughout our MSK LEG journey we have remained reflective. As with any project there have been things that have gone well and things that have not. It was important to us that we provided sufficient and appropriate insight, support and challenge to the MSK redevelopment process in order that national MSK services were developed into the best they could be and provided the public with choice. Working with clinicians in a true co-productive manner was high on our agenda. We wanted to be treated and valued as equal partners at the table.

We benefitted from good leadership, who embraced co-production as an ethos and welcomed us as equal partners to the table. Andrew Bennett, National Clinical Director was tireless in his support for us, as was Aimee Robson, Deputy Director Personalised Care Group. We needed ongoing positive championing, and this was more than ably done for us by Cristina Serrao and Helen Lee from the Co-production Programme in the National Experience of Care team. Without the leadership, enthusiasm and pro-active support of these four people we wouldn’t have been enabled to have impact and make a difference. Good and enthusiastic leadership has been key to our success.

It was important to us that the lived experience partners were diverse, both in terms of protected characteristics, skills and experience. Whilst it was not practicable to create a diverse membership from the beginning due to the suddenness of lockdown this was achieved in the fulness of time. Our insights, challenge and support are all the richer for this.

Perhaps one of the most important features of MSK LEG is that we regularly meet as a group and time has been given for us to get to know each other and grow as a team. We have gained a strong group identity. The group has evolved into a collective entity which is greater than the sum of its parts.

As well as developing the group as a team it has been important to give individual members specific roles within the team. This was achieved by assigning each member to an MSK Workstream. This has ensured that each individual member have their own sense of identity within the team, know what is expected of them, and they can get their teeth into something that really matters to them, and they have lived experience of. There have been some administrative delays in getting some of the members set up in their workstreams which is unfortunate, but those that are set up say that they value having an individual role as well as having a wider team role.

As with any team it has been important to provide good pastoral assistance to members. It could be said that good pastoral support is particularly important taken the very part time role of its members, and because all lived experience members are living with a health condition / disability that might make working more difficult than others. Ensuring reasonable adjustments are provided as needed has been key to ensure everyone has equal access to the group. This is likely to become even more important as the group moves into having some face-to-face meetings post pandemic.

Lived experience partners bring many skills and experiences but are often not equipped to understand the NHS or its ways of working. Good training provision and support can and does make a big difference. We have been fortunate to have been given access to important training.

MSK LEG was built on the principle that the insight and experience that lived experience partners bring to the table is as valuable as the insight and experience that clinicians bring, and that lived experience partners should be properly financially compensated for their work. The group has required proper funding and budgets have had to be found. This hasn’t always been an easy task, particularly as co-production in NHS services is effectively still in its infancy. However, our leadership knew that without allocating appropriate funding then the lived experience voice would be lost, and we would be back to the situation where clinicians are devising healthcare systems based on their own assumptions, resulting in sub-optimal services, and services that in practice people might not want or value. Providing adequate funding has been, and will always be, key.

**Next steps, sustainability and scaling**

MSK and other NHS services should not be devised solely by clinicians and academics. The services are there for the benefit of the patients and the patient voice needs to be heard in their design. This patient voice needs to be heard on an equal footing with the clinicians. It is only by truly listening to patients that the most optimal NHS services can be devised and provided.

MSK LEG has shown how it is possible to provide that all important patient voice into the decision-making processes, and the benefits of doing so. The group acts as an exemplar for co-production in NHS services.

NHS services who want to embrace co-production will need to ensure appropriate resources and funding is in place. It is possible they will need to argue and bid for this funding, and so it would be helpful if the benefit of listening to the patient voice can be demonstrated with data.

MSK LEG have shown how a successful lived experience co-production process can be set up within the NHS. Based on our experience and impact we strongly argue for the practice of lived experience partners to work alongside healthcare professionals when devising NHS services.

**Find out more**

To find out more please email [england.eoccoproduction@nhs.net](mailto:england.eoccoproduction@nhs.net) or continue the conversation on twitter with hashtags #MSKLeg #Coproduction #LivedExperience

[Co-producing Covid-19 recovery](http://www.ihi.org/communities/blogs/co-producing-covid-19-recovery?utm_campaign=2020_TW_Test&utm_medium=Feature&_hsmi=90381052&_hsenc=p2ANqtz-9KU2MPBwpdpOxB0yjx7D2tXoZNlspsuEluio3KikNBPmheD_ULepNJSV2KT709EKdGPO0-10mxE4RRaQXRd3CXxOk4hQ&utm_content=Co-Producing&utm_source=hs_email)

[Why do we fear co-producing health with patients](http://www.ihi.org/communities/blogs/why-do-we-fear-co-producing-health-with-patients)

[Power to the people: coproducing the national musculoskeletal strategy](http://arma.uk.net/coproducing-national-msk-strategy/)

[Valuing Lived Experience to Drive Innovation During the COVID-19 Pandemic](http://www.ihi.org/communities/blogs/valuing-lived-experience-to-drive-innovation-during-the-covid-19-pandemic)

[MSK Lived experience Themes of What Matters](http://arma.uk.net/wp-content/uploads/2020/10/WIP_20200914-MSK-Lived-Experience-Themes-of-What-Matters.pdf)