

Summer
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INVOLVING PEOPLE WITH MUSCULOSKELETAL CONDITIONS IN SHAPING LOCAL SERVICES

There are an estimated 20.3 million people in the UK living with musculoskeletal (MSK) conditions. People living with these conditions tell us that they value and rely heavily on healthcare services, but only just over half are satisfied with the support that they receive. An essential ingredient in designing services that deliver the best possible care, patient experience, and value for money, is to involve the people who will use them when shaping them.

Working with the public in this way can be hugely rewarding and a powerful catalyst for change. To support local healthcare teams, Versus Arthritis has put together a Six Step Guide to help service improvement by involving people with MSK conditions from conception to conclusion.

For more information contact
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Six Steps to help service improvement by involving people with MSK conditions.



1 MAKE THE CASE FOR BETTER INVOLVEMENT

Examine the local need to involve people with MSK conditions, as well as others such as carers or loved ones. Make sure you are well informed, being led by best practice and evidence. Use your own organisation's values and set some principles to guide you.

Map out what is happening locally and explore options to help get traction. Get buy-in from senior leaders. Allocate sufficient resources. Choose your objectives and outcomes carefully. Be clear about what this work will and won't include. Involvement is often viewed as a spectrum, so whether you seek

to carry out engagement, co-production, or other activities, use the right terminology and be consistent with your language. Consider how you will be transparent and accountable. Define how it will contribute to tackling health inequalities. Be explicit about how you will use what you learn to shape what you do next. Communicate clearly and build partnerships wherever you can.

“Patients usually only see the ‘front of house’ of the NHS. Making us part of the entire process really helps us understand the system. This was where I could see my volunteer work making a difference. Half a million people in my area could be affected by a better healthcare pathway.”

James Warren, Patient Representative, Berkshire

2 PLAN TO EMPOWER EVERYONE

MSK conditions are very broad, affecting people of all ages, backgrounds and from every part of society. Some people will have other long-term conditions too. Many people work and/or care for loved ones, and some are waiting for essential support or treatment. The symptoms people tell us affect them the most are pain, fatigue, isolation and mobility difficulties. Therefore, you should ask people how your involvement can be accessible, working in ways that suit their needs whilst contributing to your objectives. Make specific plans to be inclusive, encouraging participation from under-represented groups. Build in mechanisms to empower the right people at the right time.



Be clear on who will represent who, how, and why that approach is appropriate. Plan to be responsible about using information and make your processes clear so people know what to do if they have concerns.

Training and ongoing support are crucial, both for the people you plan to involve, as well as those delivering it. Provide staff with everything they need to do this work to the best of their ability. The culture you create and the language you use will be pivotal when it comes to empowering staff as well as people with lived experience.

3 INVOLVE PEOPLE WITH MSK CONDITIONS THROUGHOUT

This should happen as early on as possible. There are benefits to repeating many aspects of steps one and two again, sharing the decision making alongside the people you have involved. All too often we observe that project aims have been fixed by professionals alone before involvement activities have started.

Prepare to be challenged early on and embrace opportunities to change. A mix of methods (surveys, visiting community groups, panels, co-production workshops) usually offer some balance of scale and depth.

Consider developing sub-groups to feed into wider projects, and rotate representatives on panels. Building peer support between the people you involve can help.

Regularly ask everyone how things are going and document what goes well, as well as what could be better. Ensure people are feeling supported before, during and after their involvement. Consider whether the principles or values you set out to follow are being played out in practice.

“From my experience as a patient rep on a local review of rheumatology services, I think the involvement of patients plays a vital part in re-designing services. We give a different perspective on the service and highlight issues and opportunities for improvement that service providers are often unaware of, including opportunities to signpost to services outside the NHS.”
Lorraine Cosgrove, Patient representative, Flintshire



4 ACT ON WHAT YOU FIND OUT

You can avoid tokenism by having plans for how involvement will lead to service improvement. Allow time and resource to make meaningful changes to the way services are delivered as a direct result of what you have learned.

A flexible and genuine approach works best. In our experience, people with arthritis enjoy working with organisations who have an open and honest relationship with them. Progress is more important than perfection.

“The Patient Voice volunteers made a significant contribution to the design and delivery of our patient service improvement project. They were able to guide us in making changes to how we gathered information that was meaningful and important to those who use our service. We now can build and develop in a way we know is beneficial to our patients.”
Kelly Carolan, Spinal Orthopaedics Physiotherapy team, Belfast Health and Social Care Trust

5 EVALUATE YOUR WORK

Has this work been purposeful for everyone? What was the experience like for the people you involved? How did professionals find it? How could you connect with more, or different people next time? What have you learnt, and what have you done? What has the impact been?

Acknowledging any pitfalls in your approach will help other people avoid making the same mistakes again. And finally, tell the people

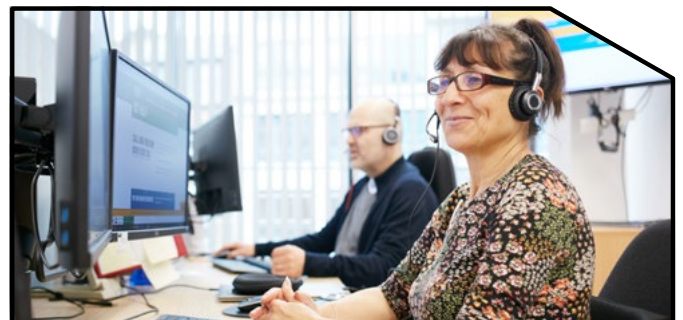
who have contributed what has happened because of their input and make time to celebrate their contribution.

“As we’ve grown our people participation approach and involved people more in the design and delivery of our services, we’ve found answers to questions we never thought to ask. We welcome open conversations about how we can do better, with the aim of doing better because of those conversations.”

**Sarah Kilby, Co-production Lead,
Ambulatory Care, Cambridgeshire
Community Services NHS Trust**

6 EMBED A CULTURE OF INVOLVEMENT

Develop a culture of continuous improvement so you can build on every action you take and develop your involvement activities in the future. Plan to share what you have learnt. Designate a lead person to communicate your work far and wide and ask others to support you to share the journey, including those who have taken part. Building long-term, mutually beneficial relationships often adds more value than one-off engagements, so stay in touch with people. No matter where your starting point is, embedding high quality involvement activities into your organisational culture will help to deliver more effective and efficient services for the people who will use them.



HOW CAN VERSUS ARTHRITIS HELP?

We have local groups, volunteers and networks that may be able to support you. Contact us at

healthservicesimprovement@versusarthritis.org

At Versus Arthritis, we are working hard to embed involvement across all our work. By using six principles we deliver involvement which is informed, accessible, inclusive, responsible, supported and purposeful.

You can join our professional network community to stay up to date with our work and hear about actions you can take to improve the lives of people with MSK conditions at

www.versusarthritis.org/professionalsnetwork