**Employing a service user as a member of a musculoskeletal (MSK) service; how to start, support and scale this opportunity**

**Stevenson K 1,2,3 , Brooks M 1, Hetherington L 4, Lench J 1, Kent A 5 , Dunphy J 6, Lubitsh G 7 and Ellis B 6,8**

**Stevenson K**

Consultant Physiotherapist, Honorary Professor Clinical Care and Leadership, Regional MSK Lead NHS England NHS Improvement

1.Midlands Partnership NHS Foundation Trust

2.Impact Accelerator Unit, The Medical School, Keele University

3.NHS England and NHS Improvement

**Corresponding author**

**Kay Stevenson** [**Kay.stevenosn@mpft.nhs.uk**](mailto:Kay.stevenosn@mpft.nhs.uk) **@kayiaupt2020**

**Brooks M**

Physical Health Peer Support Worker

1.Midlands Partnership NHS Foundation Trust

**Hetherington L**

Integrated Musculoskeletal Service Lead

Acting Operational Lead Surgical Services (Minor Surgery)

Versus Arthritis Musculoskeletal Champion

4.North Tees and Hartlepool NHS Foundation Trust

**Lench J**

Involvement Manager

1.Midlands Partnership NHS Foundation Trust

**Kent A**

Rheumatology Speciality Manager/Nurse Lead

5.Salisbury NHS Foundation Trust

**Dunphy J**

Senior Programme Lead MSK Clinical Champions

6. Versus Arthritis

**Lubitsh G**

Professor in Leadership & Psychology

7.Hult Ashridge Executive Education

**B Ellis**

Senior Clinical Policy Adviser

6.Versus Arthritis

Consultant Rheumatologist

8.Charing Cross Hospital

**Abstract**

**Background**

Putting patients at the heart of everything we do is fundamental to the philosophy of the NHS. It is required to stimulate cultural and transformational change needed to manage the increasing demand on NHS services. Patients as ‘equal partners’ are recommended by NICE, the charitable sector and MSK Best Health Collaboratives but the method to achieve this ambition is less clear.

**Method**

A large community Trust in the UK explored opportunities to employ a service user in a Musculoskeletal Interface Service. The Peer Support Worker model (temporary employment for 6 months) was used to facilitate employment. Impact of the role within and external to the Trust, was captured.

A facilitated discussion was held with National MSK Leads to highlight how organisations could start, support and scale these opportunities

**Results**

The first MSK Peer Support Worker was successfully appointed in January 2021 and became the first Physical Heath Support worker within the Community Trust. A permanent Patient Engagement Champion was secured following the initial 6 months in post.

Facilitated discussions with 40 senior MSK Leaders suggested building relationships with others internal and external to the organisation, communicating the purpose, benefits and achievements of the role were important success factors.

**Discussion**

Employing a patient with lived experience of MSK health problems can influence processes, pathways and culture within an organisation. MSK leaders are well placed to seek and create opportunities to embed such roles. Care and consideration need to be given to the mentorship and going support for post holders.

**Background**

Putting patients at the heart of everything we do is fundamental to the philosophy of the UKs public heath system (NHS Long Term Plan, 2019). It continues to be at the core of future ambitions for the NHS and for organisations, charities and collaboratives who support those with musculoskeletal (MSK) pain (ARMA, 2019; Best MSK Health Collaborative, 2021; Versus Arthritis, 2021). The Long Term Plan states that patients will have more say about the type of care they receive and NHS England and NHS Improvement Best MSK Health Collaborative has placed Shared Decision Making and Patient Initiated Follow ups as two of its eleven core recommendations (Best MSK Health Collaborative, 2021).

The National Institute for Health and Care Excellence recently published guidance on Shared Decision Making (SDM) (NICE, 2021) which advocates patients and clinicians working together to reach a jointly agreed plan about their future care. This approach, at a clinical level, encourages a shared conversation about potential treatment options, highlighting the risk and benefits of each. This process allows patients and carers to make informed choices about their current and future care. How this is offered going forward is of interest, as a recent survey of patients attending a Musculoskeletal Service (n=211) highlighted a third of patients would prefer a virtual consolation going forward (Cliffe and Stevenson 2021).

Versus Arthritis, a UK based charity, in conjunction with the Medical School at Keele University, and with funding from NHS England, have co-created a set of Musculoskeletal (MSK) Decision Support Tools to promote such meaningful consultations that are framed in the patient’s context and facilitate service users to make informed choices (Versus Arthritis https://www.versusarthritis.org/about-arthritis/healthcare-professionals/musculoskeletal-decision-support-tools/).

The National Institute for Health and Care Excellence Care, provides independent evidence based recommendations to guide practice in the UK. They suggest that NHS organisations will need to give priority to shared decision making and patient engagement at the highest level (NICE, 2021). Their recommendations include: appointing leads at a senior level, who have responsibly for embedding SDM; appointment of a ‘patient director’ and identifying ‘patient champions’. The patient director role would fundamentally raise the profile of the service user in planning and implementing the guideline and its recommendations.

Versus Arthritis (2021) also recommend involving people with musculoskeletal conditions in shaping what local services should look like. They highlight six key steps when engaging communities. They include: making the case for better involvement; empowering everyone; involving those with musculoskeletal conditions; acting on what you find; evaluation and promoting a culture of improvement (Versus Arthritis 2021).

In 2017, Versus Arthritis partnered with Ashridge Hult Executive Education to create the MSK Champions Programme – a bespoke leadership training programme for MSK health professionals. The aim of the programme was to develop the leadership skills needed to make significant shifts in the way people with MSK pain are empowered and engaged in their communities. Each participant had a dedicated project to work on through the 18-month programme. Patient engagement and empowerment formed the basis of many of the projects.

A participant in this programme led a large Musculoskeletal Interface Service and recognised the opportunity to embed service users within the MSK team. Pre Covid pandemic, this service assessed and managed over 23,000 patients with MSK pain and employed Advance Physiotherapy Practitioners (APP), General Practitioners, Nurses and Rheumatologists as the core clinical team. At an annual away day, the concept of employing a patient with lived experience of MSK pain within the team was proposed, discussed and overwhelmingly supported by the MSK team.

Whilst it is recognised that service user engagement is vital at the strategic, organisational and clinic level, what is less clear is how to achieve this ambition. The aim of the article is firstly to support those who may be exploring how they can embed service user perspectives in the running of MSK services, to highlight a local process used to recruit this role as a paid team member, to share lessons learnt and describe future aspirations. Secondly to share the views of a broader stakeholder group on starting, supporting and scaling the ambition of employing service users alongside clinicians and managers to improve MSK service provision and development.

**Method**

* **Embedding a service user into a MSK Service in North Staffordshire**

The Musculoskeletal Interface Service sits within a large community Trust in North Staffordshire. There were no existing structures or process to employ a patient directly into the MSK team, but the Trust employed ‘Peer Support Workers’. These were 6-month Band 2 secondments, requiring 15 hours’ commitment per week. A Band 2 sits within the NHS pay structure that covers all staff except doctors, dentists and very senior managers. There are nine pay bands starting at Band 1. Originally, the ‘Peer Support Workers roles were conceived to give patients with mental health issues 6 months’ employment that could act as a stepping stone to greater independence and potential future employment. The clinical lead from the Musculoskeletal Interface Service worked with the Patient Involvement Team to use this employment framework to create the first MSK Peer Support worker within the Trust as a 6-month opportunity to test the principle, measure impact and consider sustainability of the r ole. Funding was agreed, a job description and person specification (available on request) was created and the post was advertised on NHS Jobs.

* **Views of a broader stakeholder group on starting, supporting and scaling this ambition.**

In July 2021 a leadership event was run by the Versus Arthritis MSK Champions Programme attended by both cohorts of MSK Champions, representatives from Versus Arthritis and the Ashridge Hult leadership team, people with arthritis and selected NHS stakeholders. To extract learning about the MSK Peer Support Worker initiative, attendees were invited to participate in a workshop about ‘Employing service users as colleagues in MSK Services’. Following a presentation from the MSK Peer Support Worker sharing their experiences and impact to date, and from two MSK Champions with an interest in patient engagement who described their ambitions for their organisations, participants were asked to discuss the concept of Patient Employment in the NHS. The discussion was organised around themes of how to start to engage or employ those with MSK lived experience, what support is needed for such a role to become successfully embedded and how such initiatives could have more scope in.

**Results**

**• Embedding a service user into a MSK Service**

The first MSK Peer Support Worker was successfully appointed in January 2021 and became the first Physical Heath Support worker within the Community Trust. The MSK Clinical Lead provided mentorship to the post and within the first two weeks had arranged meetings with key strategic leads including the Trust Chief Executive, Head of Planned Care and Head of Commissioning. Short-, medium- and long-term (up to 6 months) objectives were co-created around four main parameters; Information; Communication; Education and Empowerment and Sustainability (See Table 1). Objectives achieved included : participating and leading weekly MSK team meetings, representing service user views in a large local MSK Service Integration project, communicating key messages to staff and patients via blogs and vlogs, participation in the development of patient videos, promoting Versus Arthritis MSK Decision Support Tools and contributing to the development of patient reported outcome measures.

As the post neared its 6-month time limit, the Involvement Team and mentor reviewed the impact of the role against the objectives. It was agreed to extend and revise the role as a Band 4 Patient Empowerment and Engagement Champion post. This is a higher pay point in the NHS pay banding. This pilot is being viewed by the Involvement Team as an exemplar of how to employ service users in clinical teams, and the post holder and Clinical Lead are now engaged in translating the model across the Trust.

Some reflections on the experience by the post holder are shared in Figure 1. Reflection of the post holder from the MSK Operational Manager suggested this role is a ‘*much valued resource in enabling our MSK services to develop by ensuring the timely engagement and contribution of the patient voice. They have reached out to other service users to expand the network of patient representatives and has been exceptional in sharing his experiences of working closely with system wide and MSK leads to enhance understanding and invite contribution from wider patient groups’.* An Advanced Physiotherapy Practitioners suggests ‘*the role has been instrumental in facilitating a collective and collaborative shift in thought, to one that has the patient at the fore. His presence in meetings and work groups, making me (and hopefully others ) consider at least, “what will our he say about this”. This can be translated into “what does this mean for the patient, have we truly considered the patient in this”*

**• Views of a broader stakeholder group on starting, supporting and scaling this ambition.**

A total of 40 people participated in a 40-minute learning event, identifying key issues that have been grouped into themes in Table 2. In each category, building relationships with others internal and external to the organisation, and communicating the purpose, benefits and achievements of the role emerged as important success factors. The learning from the workshop was subsequently used by another MSK Clinical lead who was present to inform the development of a Patient Engagement Strategy for a large Community Trust in the North East of England.

**Discussion**

The ambition to ensure patients are engaged at every level of the NHS is vital to the future transformation of our health and social care services. Our service users should be fully empowered and supported to share not only in decision making around their own care but they should also be employed as transformational leaders within our teams and organisations. If the biggest challenge facing the NHS is a cultural one (Ham et al 2018), where relationships between NHS, patient and the public need to be transformed, providing patients with new opportunities to contribute and lead is essential.

Our work provides an example of an organisational mechanism that could be used to employ patients with lived experience within clinical teams. By opportunistically using the existing ‘Peer Support Worker’ role we were able to demonstrate impact and then create the more permanent, and better paid role of ‘Patient Engagement and Empowerment Champion’. The role has changed the MSK model in several ways. For example the patient voice is now being represented in all MSK operational and strategic meetings. This is helping to change the culture as it is now expected that a service user would be in attendance and participating in discussions. They are communicating through videos, blogs and newsletters about the MSK services. As this comes directly from the Peer Support Worker, it has greater impact. Ideas for improvement being generated and led by the Peer Support Worker e.g. use of Decision Support Tools. The lessons of incremental change followed by evaluation and follow through may be useful for others trying to shift local practices and culture in health provider organisations which can sometimes be bureaucratic and inflexible.

From our experience, time and consideration needs to be given to the role requirements and the training and support needed to allow service users to fully participate. This may range from the skills required to join team meetings on an IT platform to helping post holders in sharing experiences and opinions in a more public setting. The manager/ mentor of the role also need to be flexible, supportive, available and be able to coach and develop those who bring a different kind of expertise to service improvement. They also need to be aware of how to support the whole team if challenges are raised by the service user. Empowering leadership is required to allow all stakeholders to participate and gain the most from the shared experience.

This role is in keeping with what NICE recommends in its ambition to embed shared decision making at an organisational level, and mirrors the patient director role who would be responsible for raising the profile of service user in planning of services (NICE 2021). The impact of the role has been far reaching and has included participation in key musculoskeletal service transformation projects. There has also been culture shift, so whereas before a patient voice was not routinely directly heard at management level, it is now commonplace to see an employed patient representative leading our MSK team meetings, participating in clinical and strategic discussions and challenging the status quo. The limitation of this work is that this has only been achieved in one MSK service in one Trust in the UK. Scalability of such posts across the system needs to be implemented, and the impact more formally evaluated.

The key themes highlighted through discussions held at the Versus Arthritis MSK Champions event are in keeping with the key messages of empowerment and engagement shared with NHS and the MSK Charities (NICE 2021, Versus Arthritis 2021). They provide some useful tips to consider at each stage. Perhaps unsurprisingly, communication and relationships are key success factors, appearing in both start up, support and scale sections. To be successful these roles need senior support, guidance and mentorship to ensure they are embedded in the organisation, with clear achievable aims and objectives and empowered to contribute in all areas, regardless of their experience of working in NHS services.

In summary we have described how employing a patient with lived experience of MSK health problems can be employed to influence processes, pathways and culture within an organisation. MSK leaders are well placed to seek and create opportunities to embed such roles. However, these roles do not replace the need for all across the system to be attuned to the needs of service users, especially the seldom heard voices, but hopefully will act to enable and maximise their participation. Care and consideration need to be given to the mentorship and going support for post holders. Themes have been identified to be aware of in each phase of the post’s development, and communication and relationship building emerge as important success factors throughout. If well designed and supported, such posts have the potential to achieve a much-needed transformation in NHS culture.

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Table 1 Six months objectives for the MSK Physical Health Peer Support Worker Role

|  |  |
| --- | --- |
| **Short term goals (month 1)** | • Meet Chief Executive and senior NHS and CCG leads  • Embed into all Musculoskeletal integration meetings  • Give opinion on Patient Experience Measures Project  • Consider capturing the experience, what this role it has meant to you?  • Consider the ‘education’ project? Share what you are learning with public  • Set up communication strategy- twitter/face book  • Consider funding application to Haywood Foundation Charity to fund an interviewer  • Written report at end of first and end of each month ( to key leads)  • Local radio interview  • Link with charities MIND and Versus Arthritis |
| **Medium**  **(month 2-4)** | **•** Ensure ‘Education’ project underway  • Start to consider future funding  • Link in with Social Prescribers / Patient Information and Education Room  • Consider a Rheumatology project  • Link to BeeFree project and its output (<https://Beefree.org.uk>) and promote |
| **Long term**  **(month 4-6)** | Consider funding application and what data we would need  • Write up experience |

Table 2 How to ‘**start, support and scale’** embedding patients into clinical services: Themes identified in discussion

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| --- | --- | --- |
| **Start** | **Support** | **Scale** |
| **Use what is already available**  Look at existing models e.g. Sussex, Midlands Partnership NHS Foundation Trust  NHSE Peer Leadership Course  Versus Arthritis (Involvement Network)  Are there existing volunteers seeking opportunities  **Seek strategic buy in**  Link into Trust strategic objectives  Seek executive sponsorship  Get clinical team on board  Involve commissioners, managers and voluntary sector  **Consider governance**  Consider a patient forum charter that everyone signs up to  Consider and plan for the unintended consequences  Have a clear framework for accountability  Identify a budget  **Consider the role**  Find a model that suits your context e.g. employment  Define the role you need with clear purpose  Consider the roles values and principles  Have clear topics and goals  Consider how you measure impact  **Communication**  Define and communicate outcome  Identify local groups or individuals  Build links with existing groups  Involve Trust Charity  Encourage and support patient using blogs/vlogs  Highlight benefits of patient engagement to all  Needs to be visible  Patient involvement from the start | **Engage others**  Involve Versus Arthritis  Link with NHSE and NHSI Patient Experience Leads  Jointly agree Terms of Reference  Link in with other services who have done this before  Equality of representation  **Communication**  Engage in feedback to patients  Share case studies, how is the post/s making a difference  Spread the knowledge  Multiple channels for involvement e.g. virtual forums, workshops, focus groups  Utilise complaints, example of where you can make a difference  Use design workshop template and consider external facilitation  **Consider culture and context**  Challenge colleagues and teams  Breaking down barriers  Culturally sensitive  Describe what you mean by Peer Support  Consider alternative funding mechanism | **Show impact**  Provide value for money  Provide evidence of impact/tangible change  Provide evidence that it works  360 feedback for patient engagement roles  Provide evidence of improvement and change  **Ongoing support**  Mentoring and training of other patients  Training patients for the role of peer support  Use Business Case  **Communication**  Marketing strategy  ‘You said, we did’ methodology  Storytelling to CEO of Trust |

Figure 1 Personal Reflections MSK Peer Support Worker

*“Putting patients at the heart………” is certainly happening, from my experience. Since being appointed as the first physical health services Peer Support Worker by the Midlands Partnership NHS Foundation Trust I have been privileged to have numerous opportunities to contribute the ‘patient voice’ to a wide range of projects and initiatives. The variety of projects and the scope of my involvement has been truly amazing – from a large services integration programme to evaluating the patients’ response to numerous patient-focused resources has been both interesting and stimulating.*

*To be encouraged to develop my role by my inspiring mentor, to receive invitations from some august bodies – Versus Arthritis and Keele University – and to develop meaningful relationships with the equally inspiring musculoskeletal interface service team in which I am currently embedded is evidence that “putting patients at the heart of everything” does work when there is an appetite to do so. There is evidence that there is an appetite for this and the role I occupy; instanced by numerous other faculties within my employing Trust to replicate the initiative and other Trusts around the UK developing similar roles which I am also being privileged to contribute to.*

*My experience is so overwhelming positive. I cannot do more than endorse the concept of employing service users with lived experience wherever possible and appropriate.*