



How have we harnessed the power of patients as partners?

Transcript

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We're a very big, varied group with incredibly diverse backgrounds and knowledge, but we all need to use the MSK services, which is how we are part of it.

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It's been a fascinating experience to be a patient partner because being a patient partner at MSK puts you right in the center of decision making. And that's what the MSK partnership focuses on, is patients. It's patient centered and it is unique in its approach. And I've been lucky enough to be part of some really groundbreaking work to initiate new processes and systems that make the best use of technology in these changing times and it's been a brilliant experience.

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Yeah, my experience is also it's given me so much pride, that I sort of almost written myself off as not being use to anything because I wasn't really contributing to work and everything because of my health. And and this has helped me use, you know, rediscover those skills that I had and and feel like I'm adding to society, I guess.

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I mean, I just love the fact that this has given me purpose and I didn't have purpose before. So that's been astonishing for me. But working with this group of people, I just love because amongst us, amongst this team, we have so many different ways of thinking about things. We have so many, such a range of experiences that people bring to the group. And it's too easy for people who work as patient partners to be seen as patients rather than to be seen as themselves, with a lifetime of skills that they bring. And that's the range we have, I think is just terribly important.

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I think it's really refreshing when people come to you and say, what do you think? What worked, what didn't work, what could be made better?

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This was my first role within the NHS, in patient co-production where I'm drawing on my own lived experience as a patient to improve services. And I must admit that when I first considered the role, I was warned by NHS colleagues from a different organisation, that sometimes patient co-production work can just be seen as box

ticking, where contributions aren't really kind of meaningfully implemented, but rather it's just seen as something to make the organisation look good. But my experience of being a patient partner within Sussex MSK, is I've always felt valued by the staff.

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I've always felt recognised and I can quote multiple contributions I've made that I've actually made a difference to the service.

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And the biggest challenge that I've experienced has been when I've been observing clinicians in clinics and so on. And it's quite obvious to me that the I.T. systems sorry, I'm on it again, but I.T. Systems in hospital settings and clinic settings are just not up to modern standards in terms of the sizes of CAT scan files and that sort of thing.

And that does impact on the quality of the clinical interactions that the clinicians are able to have with patients. And that that I think going forward in years to come is something that really seriously needs to be addressed.

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Well, of course, the big elephant in the room is COVID.

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One of the most startling and astonishing moments I've had was the first zoom meeting I joined during the recovery development when instead of seeing lots and lots of fit, healthy young people doing all the things they normally do around the MSK building, I was faced with this sea of exhausted people who had just been working so hard and were continuing to work so hard. And it was so it was a real showstopper for me.

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But the thing with the COVID-19 is it's meant that we've had to kind of step back. And I'm very I've gone into that mode. I'm very aware of it, of people are so busy, the connections and everyone has been so busy trying to keep the service running. Keep people going. Physios are great, greatly needed now in the recovery and how we can be seen as being positive and helpful.

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So what I want say alongside that is I hope people realize just how thankful we are for that work that goes on, because the sense of sometimes, you know, they're not recorded.

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I think one of the biggest helps is that we worked on, when we actually went and looked at how clinicians were talking with their patients for shared decision making, that was such an interesting exercise. And I think clinicians also appreciated our worth. But of course, we are in a slightly changed landscape like having to do this meeting via technology.

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My challenges have been a few challenges that we faced or faced as PCP, especially like COVID, which has been a big thing, as Jane said, because I find like with some of the projects that we are trying to do, like consultations for online consultations has been quite difficult to try and get emails and phone calls and phone numbers for the patients in order to carry out the patient's feedback through virtual consultation. So there has been a big thing because we've been really excited

wanting to go ahead with a project, but we're finding it very difficult. I know the clinicians are quite busy and it's a difficult time, but I think the communication between the two would be great if we managed to sort it out. Also, I think maybe balancing the patients frustrations through self referral forms or maybe mechanisms of how a patient's appointments work. So there's quite a few things I feel like there should be improved.

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For me there when I'm saying if the challenge is there are two things. We're it maybe makes sense, we are not fully in the system, but sometimes there's a bit, because we are not fully in we don't fully know where to go. And it it doesn't matter even if you're within a system, it takes a while to build up relationships. And it is a problem even if you're deeper into the system. But you change positions and you have to build up new relationships. And that's a struggle you have wherever you are. But depending on where you are, how you get looked at, that can be easier or more difficult, and especially if you haven't got access to certain information as you are not fully in the service. Otherwise, to me, that's the one thing, and I don't want to see it as a challenge, but the, I'm sight impaired, so I've got some other issues which aren't really part of what the service is catering for, but, the acceptance and the double checking and how to getting that included to make it more inclusive. For me, the interesting thing here is I've noticed David and I, we had discussions quite at the beginning how he could help me etc. but I don't have to remind David in the same way as so often in other environments, I have to remind people.

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I think the important thing I think is this is value of partners, of patients that actually that shared decision making work, of actually treating people with respect, similar to what Abby said about breaking hierarchies, that, OK, this is the clinician that knows more than you. However, you know your body better than anyone else.

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Collaboration, removing hierarchies, taking things forward into the next century.

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I think patient centered care, empowering patients to take responsibility of their own treatment and also the partnership between the patients and the clinicians. It's it's great.

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And so what's been so enlightening and wonderful is that you have this the staff who answer the phone, who actually try and fathom their way through and understand what the patients need. And they so we've worked with them. I've been on projects working, as to how helpful they are. And that's, they want to make everybody's life easy, for themselves and for the patients. And it really does work. And you see it in action.

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I just hope, with making the outside world more aware of us that others could copy us. What we're doing and I think, that we just need the help.

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How I wish we could clone the service and spread it around the NHS and also spread the founding principles of the MSK partnership around a little as well,

because I think the ethos of the organisation is what makes having a patient director and patient partners as successful as it is.

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And I really do think it is successful in bringing about change, doing things differently, recognising opportunities and maximising those opportunities.