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Steven Bettles: Hello and welcome to the General Osteopathic Council podcast. In each episode, we speak with experts and colleagues about topics affecting the osteopathic profession and our work as regulator for osteopaths. Answering questions we get asked a lot by osteopaths, patients and members of the public. I'm Steven Bettles, Head of Policy and Education at the General Osteopathic Council, and I'm joined today by my colleague Rachel Heatley, who is one of our Senior Policy and Research Officers.

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Steven Bettles: Hi, Rachel.

Rachel Heatley: Hi, Stephen. It's lovely to be here today. I'm really looking forward to chatting with you. This is my first podcast with the GOsC. I have done one or two before, but this is all a learning curve so listeners, bear with us.

Steven Bettles: In today's episode, we're going to discuss how we as an organisation engage with patients. How do we get the patient's perspective on the work we do and why this is important?

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Steven Bettles: And a little later, we would take a look at a couple of the examples where patients have been involved in our work and have helped us to create something useful for the profession. Before we do, Rachel, you've been central to the GOsC's work with patients over the last couple of years. Could you give our listeners a quick overview?

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Rachel Heatley: Sure, Steven, I'm happy to. I'll just kind of say from the outset that working with patients has always been very important to us and we kind of communicated with patients a lot in terms of inviting them to participate in surveys and provide feedback on our work. But I think the turning point for us was during the pandemic, there was a recognition that, you know, across the health sector, patients had been disenfranchised from policymaking.

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Rachel Heatley: And, you know, there were quite a few charities like National Voices and the Patients Association who were producing reports that were quite worrying about that aspect of health care. And I think it was it was a reality check for us as well. And we reflected on what we as an organisation needed to do, because as a regulator, you know, our statutory duty is about protection of patients and the public, and we can't do that if we're making assumptions about what patients think and are concerned with.

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Rachel Heatley: And you know, what works well. So I was given the opportunity in the team to go and speak to experts in the field of patient engagement. I spoke to, you know, the NHS England. I got to speak to Jules Simmons in University of Leeds Medical School has been a real pioneer in this area. And I think, somebody who was extremely helpful was David Gilbert, who is the former patient director in the MSK area in Sussex.

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Rachel Heatley: And what we kind of learn there was about how we should go about it. So, there's no one size fits all for patient engagement. It needs to be relevant and kind of adapted for the people that you're working for. So we really wanted to bring patients on board. And one of the first things we actually did was conduct some focus groups of patients about their perspective and thoughts on osteopathy in the context of Covid.

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Rachel Heatley: That was really insightful. And I think it was it was a big success in terms of how the focus groups went, how patients really felt listened to. And so we took that forward as a model for the organization and, you know, taken all this best practice and talking with experts and most importantly, listening to our own patients, we decided to set up the Patient Involvement Forum in 2021.

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Rachel Heatley: And that's been a really key driver for kind of incorporating the patient voice in our work. And I have to commend particularly osteopaths who have referred their patients to us because they have such a commitment to, you know, patient safety. And I really, really appreciate that. They've been very warm towards us. But we've also worked very closely with, the Patients Association and Healthwatch who have been instrumental in getting patients involved in our work and joining the Patient Involvement Forum.

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Rachel Heatley: So, as you well know, we've gone from a dedicated small cohort of patients to around 40 members of the Patient Involvement Forum that's been since 2021. So it's something we're all very proud of.

Steven Bettles: It's been a big change over the last couple of years, hasn't it? So I've worked at the GOsC for coming up for about eight years, and in all of our policy work, we always had the intent and the aspiration to involve patients and we did that.

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Steven Bettles: But as you say, it was a sort of a fairly small group of fairly dedicated patients who were involved in consultations and focus groups and policy discussions and the like. And this has been a massive shift over the last couple of years, hasn't it? So can you say a bit more about that and how we went about that.

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Rachel Heatley: Yeah I think that's, that's a really interesting point. I, I actually think it comes down to, well first of all formalising things. And I think when you do that, when you create a structure and I think that kind of gives you a credibility with others to show that you're really committed to this, that it's not tokenistic. And for us, it's absolutely not.

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Rachel Heatley: And I say that very sincerely. You know, when we spoke to experts, they said that we had to create and this was a term that I hadn't been familiar with 'psychologically informed spaces'.

And so what that means in reality is that you understand that patients are members of the public or individuals who are coming to you to share their views, but often have a lot of vulnerabilities.

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Rachel Heatley: We have patients who have chronic health conditions, who are often in a great deal of pain, who have extremely valuable experience, but perhaps have had no opportunity to share their experiences. So whenever we conduct any kind of engagement activity, and that could be having a phone call or a focus group or a workshop, we speak to individuals beforehand and say, what is it you need?

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Rachel Heatley: It could be more breaks than normal. It could be that, if it's a face to face event, to ensure that all their accessibility issues are catered for. We have some patients who, for example, are partially sighted so we make sure that we address their needs. And I think that's been very powerful because some of the other experiences that they have had have been tokenistic.

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Rachel Heatley: It's been, oh, we need a patient to, you know, to say that they've been able to participate, but it hasn't been perhaps meaningful or real. And as I used the word before, it's been tokenistic. And that's the opposite of what we wanted. And I think as a result of that and acknowledge vulnerability, but also acknowledging that they have such a wealth of knowledge to share.

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Rachel Heatley: I think that's been a big factor in the success. And I think it's also snowballed in a way, because we've had a few patients who have really enjoyed the work that we've done, because, as you well know, Steven, I, try to be quite a light hearted person. I think that's very important as well. And I genuinely, personally am interested in people.

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Rachel Heatley: And I think a lot of the colleagues that we work with are like that. And people know when you're being genuine and warm. And as a result, we've actually been able to recruit quite a few patients through other patients who have had positive experiences. And I think that's very important. And I suppose lastly, on that point, I would say we endeavour to provide feedback to patients.

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Rachel Heatley: So, for example, if they've participated and say they've even just completed a survey on a policy that we're creating, I will always go back to the patients and say, "Okay, your feedback was X. And as a result, here's what we did". And if for example, it informed a paper or that goes to Council or the Policy and Education Committee, I then make sure to send them a copy if that's of interest to them.

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Rachel Heatley: So I think it's authenticity, transparency and genuine desire to hear what they have to say.

Steven Bettles: And what's the work towards this so far? What have we learned from patients over the last couple of years since the Patient Involvement Forum was established in its current form?

Rachel Heatley: Oh, that's a good question. I think I would need all of the podcast series to say how much, you know, we've learned and what patients have taught us.

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Rachel Heatley: I think a lot of it is about rich insights and helping us see things through their eyes, walking a mile in their shoes. And I'll give you a clear example. I think one of the big pieces of feedback, certainly early on, was with regards the language that we used and the number of acronyms. And I'll never forget, what we tried to always do, no, not try to, we always send information ahead of schedule, giving patients a real breakdown of what is going to happen so that they feel confident taking part.

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Rachel Heatley: And how I used to name the document was a 'briefing document' about whatever it was going to be. And I'll never forget speaking to a patient who dropped me an email and said, actually, Rachel, I have a few questions. Would you be free to have a chat and talk them through? And I said, absolutely. So, you know, gave them a call, answered all the questions.

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Rachel Heatley: And then just as we were about to hang up, he said, Rachel, you know, I don't work for MI5 and I was like, yeah, I do know that, you know, why do you have to call it a briefing document? And I thought, oh, oh, I see, and he also he he's a very meticulous guy and I've so much time for him.

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Rachel Heatley: And he said also you've you seven acronyms in the document and I went "Right, ah, okay". So from that point forward I never used the word briefing document. I endeavour to remove all acronyms, but I think that's an important lesson because clean language is important sometimes as health regulators and anybody working in the health sector, whether that's regulation or clinical care, sometimes we communicate with patients and we forget that they don't necessarily have the health literacy levels that we need to adapt our communication so that they can effectively engage with us.

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Rachel Heatley: So I think plain language, richer insights as well about the work that we do and even just having a patient in the room a lot of the time focuses all of our kind of work that once they raise their voice, you think, oh, whoa, whoa, whoa, there's a patient here in the room. Everybody stop and listen and see what it is they have to say.

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Rachel Heatley: So I think those are some of the things. But as I say, Steven, you and I could talk about this for another four to five podcast files. I'll stop there.

Steven Bettles: That insight you mentioned about the insight that we've gained from patients. How is that insight sort of tangibly helped to shape some of the work that we have done over the last couple of years.

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Steven Bettles: Can you give us some examples?

Rachel Heatley: A long term project of ours has been, creating shared decision making resources, and that is a big focus of the three year continuing professional development scheme. The new one that was brought in in 2019, and one of the mandatory parts of the scheme is about communication and consent. And we know that patients are extremely satisfied with their care if the care was osteopaths, and often that's why osteopaths, when they tell their patients about the patient involvement form that they get involved.

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Rachel Heatley: So there is a real trust there. But one of the things we did discover is that sometimes some of the issues that patients experience are kind of things like helping you take control of your care. That's kind of one of the dynamics. And then the other is making a plan of action with you. So we've kind of done this, a long term piece of research with academics in Oxford University to see what we can do to create resources so that patients and practitioners and osteopaths so that they can make more explicit what's important to them so that they can share their values.

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Rachel Heatley: So that's a long-winded way of saying it's about improving communication and what we realised when talking with patients is that there needs to be a myriad of approaches. There's no silver bullet. So through the shared decision making resources project, we created audio recordings. We created an animation, we created some kind of posters for osteopaths to put up in their clinics.

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Rachel Heatley: And that was really helpful. And it got a lot of positive feedback from patients. And actually the patients association provided us with lots of helpful feedback, which then we incorporated. So we actually had lots of iterations of those resources. And we didn't just kind of send them out to the world. What we're committed to doing is doing with patients, not for.

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Rachel Heatley: So before we even considered how to implement the resources, how to evaluate them, before we put pen to paper, we met with patients and said what do you think of the resources as they are? And they had several changes that they thought we should make and help to inform the design. And then they also help to inform the implementation plan.

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Rachel Heatley: They gave us ideas about organisations that I hadn't been aware of before. Quite a few of our patients, for example, are involved with Healthwatch, other charities, local community groups. And so they gave us insight and help and often kind of connections as well, contacts that we could get in touch with to say, we think you should approach X, Y or Z.

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Rachel Heatley: So that was really, really helpful. And an interesting part of the project was for the first time, we commissioned an evaluator to look at the resources. So as part of that, we wanted to make sure that we were getting the right person. And so one of our members of the Patient

Involvement Forum sat on an interview panel alongside GOsC staff to select a researcher and having patients make that decision with us and help to inform.

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Rachel Heatley: It was really important. And for patient engagement, the gold standard is coproduction, and to have that project were really from start to finish patients were involved, they shaped the design, they shaped how we communicate it about the resources, they shaped who we chose to evaluate them. And then as part of the evaluation project, patients and osteopaths were consulted very extensively.

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Rachel Heatley: And so now those have been tested. We're going to produce another iteration. And I know that that seems like a lot of work. I think that's one of the big challenges with it. Patient engagement, to do it right, you need to invest the time and energy. Would you agree with that, Steven? Would that speak to your experience?

Steven Bettles: I do, you know, for listeners who don't know my background, I am an osteopath and I have worked in practice over many years.

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Steven Bettles: Although I don't see patients currently, I'm still registered, and I think there's a parallel between the sort of work that as an organisation which want to do to understand the patient's perspective and to hear the patient's voice and to work in partnership with patients. There's a parallel between that, I think, and the expectations on osteopaths and what the practice standards say in terms of, you know, giving patients the information they need to make choices about their health, talking to them about benefits and risks in terms of if we look at C1 of the practice standards, one of the explanatory paragraphs under that standard, and the standard itself is about being able to conduct

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Steven Bettles: an osteopathic patient evaluation, deliver safe, competent and appropriate osteopathic care. And one of the examples of what that means is to develop and apply an appropriate plan of treatment and care based on the working diagnosis. So that's fairly obvious. The best available evidence. And that's not, you know, evidence and may or may not be strong for a particular approach, but it's how you know, how that's discussed

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Steven Bettles: with the patient and agreement gained and the patient's values and preferences as a, as an integral part of that. And I think it's perhaps that bit that although patients when we've done surveys of patients in the past and they've demonstrated really high satisfaction levels of osteopaths, you know, they feel better for seeing them that that element about the values and preferences was the bit that perhaps wasn't always fully explored.

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Steven Bettles: And obviously the skills, experience and competence of the osteopath as well has been integral to that. And it seemed to me that I think as a as an organisation, our work with patients kind of, you know, we expect osteopaths to work in partnership with patients; patient partnership.

But as an organisation, perhaps we haven't always done that as well as we could to understand the patient perspective.

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Steven Bettles: And it's very easy to make assumptions because we all are patients of somebody and you kind of think, well, we don't need...

Rachel Heatley: True.

Steven Bettles: We don't need to talk to patients because we're all patients. We know what it's like to go to a GP. We know what it's like to go to a dentist or to see an osteopath or whatever, so we can bring that experience to our work at the GOsC, on Council or on a committee or whatever.

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Steven Bettles: But the insight I think, that we've gained over the last couple of years is demonstrated that that sort of that isn't enough. And, and to talk to each specifically because they're a patient is the integral element. And it doesn't matter what else they do, what their background is. You know, there are some, some, some happy bonuses because some of them are pretty high flying and have a wealth of experience that they can bring to that role.

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Steven Bettles: But we're talking to them not because they're the chief executive of a charity or a retired psychiatrist or whatever. We're talking to them because they have experience as a patient, and they want to bring that perspective to us. And so I think it's important. Yeah. It struck me that we know that as an organisation, we don't make assumptions about, you know, what patients think.

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Steven Bettles: And as a practitioner, it's very easy sometimes to think, to think or say that, you know, well, my patients think this, you know, and there may be lots of unspoken things that patients don't say, you know, but if you've never asked, you know.

Rachel Heatley: Yeah, exactly. How would you know?

Steven Bettles: They may be tolerating all sorts of things because generally they feel better, but there are lots of things that they might want to enhance or change

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Steven Bettles: perhaps, you know, so unless we actually understand what's important to patients and what you know, that, you know, it's difficult to, to make fully informed decisions in partnership with patients. It's good for them. What I'm saying in a somewhat rambly way now, but that's what I was trying to illustrate, I think, was the parallel between what we do as an organisation and what the standards ask of osteopaths as well, in relation to patients taking their views into account, acknowledging their own values and preferences, and thinking about what that means in the context of what we do.

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Steven Bettles: What about the future? What our plans for the next few months in terms of patient involvement? Is anything changing, or is there anything particular project that we're seeking insights on from your perspective?

Rachel Heatley: Oh, very good question. Very exciting. But I say challenging, in a good way, times are ahead. So as I mentioned before, co-production really is the gold standard for anybody

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Rachel Heatley: that's doing patient engagement and doing it well. And it's really been an iterative process for us. So really steep but wonderful learning curve and the next step is to reach the gold standard. So when I say that we have got approval from Council to recruit two patients to sit on Council and having patients at that strategic level involved in governance, I don't say this lightly,

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Rachel Heatley: it is a big deal. Having them involved in decision making, having their insights is just wonderful. It's something I think we're all really proud of throughout the organisation that we've managed to achieve this because it is, in a way, something very different. Very few organisations do it. And so we're really pioneers in it, but we want to do it right.

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Rachel Heatley: So it's not going to be in the next month. We want to consult with patients and of course council to say, okay, what will this look like. So I have I have written quite a few papers for Council and the Policy and Education Committee, and they've been heavily involved in shaping what it will look like. The next 6 to 12 months will be about creating the parameters, trying to think of a better word.

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Rachel Heatley: You know, in my mind I'm thinking, how would a patient describe it? What would be the clearer language? What would be more accessible? I think what will it look like? We need to, you know, get job descriptions. We need to really think how do we try to do to say, okay, where do we want to get to? What qualities and values and experience do we need from patients?

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Rachel Heatley: What can we do to create the right space for them to contribute in a meaningful way? So that that's kind of what we're aiming for, for 2025. And although that seems like far away, it certainly isn't. And we want to get this pilot right because it is it is innovative. It is something different. But because it's so different, there's always that, you know, desire to get it right.

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Rachel Heatley: And if you haven't done it before, it has to be a learning curve. And as I say, we've come a long way since 2020. But I think there's there is more to do. And having patients involved at that top level, honestly, if I didn't believe in it, I wouldn't have pushed so hard for it. I think it's going to be really, really insightful and helpful and be a wonderful addition to the work that we do.

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Steven Bettles: Yeah, no, I agree. I mean, it's for anyone who isn't familiar with the make up of our Council. I mean, there are lay members of council, there are osteopathic members of council, but there isn't a specific patient voice. And we and we, you know, we kind of gather that in other ways. And we present that to committees and to council to inform the decisions that Council make.

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Steven Bettles: But there isn't that kind of first, first hand experience of, of that representation. So this does feel kind of an innovative approach in terms of regulation, I think from what we do. Yeah. So Rachel, thanks so much for joining me today and explaining so clearly what you've been doing with patients and the work that we do as an organisation overall, if any of our listeners would like to find out more about the Patient Involvement Forum or know a patient that might be interested in joining, you can look at our website, osteopath.org.uk, where you'll also find the shared decision making resources that we were talking around and about earlier.

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Steven Bettles: The links for these will be in the show notes for this episode. So Rachel, thanks once again for joining me. It's been great talking to you.

Rachel Heatley: Oh thanks, Steven for the opportunity. Really appreciate it. And I hope people enjoy the podcast.

[Outro music plays]