

**InformED podcast Transcript:  
Delivering Patient Centric Publications  
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*Adeline 00:04.503:* Hello and welcome to InformED, a podcast series where you will hear industry experts share their thought-provoking insights and lessons in the field of medical communications. This series is brought to you by ISMPP and is generously sponsored by MedThink SciComm. The opinions shared by the presenters today are our own and do not represent those of our employers.

My name is Adeline Rosenberg and I'm the guest host for today's episode. I'm a patient advocate and senior medical writer in the patient engagement team at Oxford PharmaGenesis and a doctoral researcher at King's College London's Centre for Pharmaceutical Medicine Research with a focus on patient involvement in publications. I'm joined today by our guest speakers Trishna Bharadia and Gavin Jones and all three of us are on ISMPP's Patient Engagement Taskforce. Trishna and Gavin, would you like to introduce yourselves?

*Trishna 00:53.312:* Hi, I'm Trishna Bharadia, and I'm a patient advocate and patient engagement consultant with a particular interest in patient involvement in scientific publications and health information. I work with multiple stakeholders, including pharma, CROs, patient groups, med comms agencies, and medical publishers to better embed the patient voice in the healthcare ecosystem and medicines development lifecycle.

Like you, Adeline, I'm also involved with King's College London's Centre for Pharmaceutical Medicine Research, but as a visiting lecturer on patient engagement. I'm also an advisory board member for the UK's Patient Information Forum, an honorary member of the Faculty of Pharmaceutical Medicine, and I'm an ambassador and patron for several health and disability related organisations.

*Gavin 01:54.362:* And hello Adeline and Trishna, I'm Gavin Jones, I'm patient centricity lead at Open Health. Open Health is a global organisation of healthcare communications, HEOR and patient engagement practices. I come with over 25 years industry experience and around seven years of those I've been working at the intersection between patient engagement and medical affairs. I'm a trustee of a patient advocacy organisation in the UK, and I'm also an active member on the focus area working group towards patient centricity within the Medical Affairs Professional Society.

Recently, I helped coordinate the development of a white paper that was on the topic of embracing the patient voice within publications and it partly inspired this podcast so I'm delighted to be here today.

*Adeline 02:55.643:* That's great. Our topic today is delivering patient-centric publications. And why is this such a hot topic? Trishna, could you take that one?

*Trishna 03:17.319:* Sure. So firstly, the democratisation of information and the open science movement is making more information more accessible to wider audiences. And this means that the information out there needs to be suitable for these newer audiences. There's also been a general move over the years towards a shared decision-making healthcare model. And that means that patients need access to good quality, relevant and appropriate health information because this will help them to become informed patients and better able to have those valuable

conversations with their healthcare providers, giving them the opportunity to play a key part in the decisions that are being made about their care, about treatment pathways, services that they might require, really anything to do with their health care.

And then on the industry side of things, industry has started to recognise the value of patient centricity throughout the medicines development life cycle, which should also include publications. And linked to this, we now have industry standards and best practice like Good Publications Practice. There's been advocacy for patient involvement in the publications process, which is helping and guiding industry in the development of patient-centric publications.

So we've got this call for patient involvement in the publications process, and that's being supported by the development of industry standards and best practice like GPP. Particularly in an industry that is as highly regulated as pharma, I think it's really important that there are standards and guidelines in place and that are being developed to provide that reassurance as companies embark on essentially what is a new territory.

And then finally, I think there is an appetite amongst patients to be involved in publications. This has been demonstrated by the rise in patient authored publications, particularly in the last few years. And so publications need to evolve to better support and incorporate them. So we're not going away. And that's really why I think patient centric publications has become such a hot topic, especially in the last few years.

*Adeline 06:01.693:* So clearly, this is a really topical and rapidly growing field. Gavin, can I ask, how can we make publications more patient-centric?

*Gavin 06:15.227:* Well, I think there's two foundations to ensuring that we make publications more patient-centric. And the first foundation is ensuring that patients and advocates are involved in publication processes. Trishna referenced GPP, and I'm going to quote from the latest version published in 2022. And here's a quote that I think reinforces the need to ensure that patients are fully involved in publication processes. 'Patients and patient advocates may be included in publications planning and development, including as authors or contributors to publications as appropriate to the topic or to the therapeutic area'. Clear guidance there and we'll come on to what this could look like in the real world a little later on.

But I just wanted to take a moment just to reflect that we need to recognise the value of patient input into publications and the patient advocates that are ready and mobilised to support us. They, like us, have bills to pay and it's important to recognize the value that people like Trishna bring to our work. And therefore, we need to ensure that there's fair market remuneration for their involvement. I think let's just set aside co-authorship activities at the moment because I think opinions are emerging and we're seeing various company positions and the emergence of guidance. But setting aside co-authorship activities, fair market value remuneration for other activities should be seen as a necessity.

*Adeline 08:04.986:* That's a really good point. So you mentioned two foundations. Can you tell us about the second?

*Gavin 08:13.473:* Yes, the second foundation is patient involvement in ensuring that information related to publications is in an accessible and digestible format. We all recognize that we live in a digital world where access to information about diseases and treatments is huge. And it can be overwhelming for patients and caregivers, especially when that information is inaccurate or

contradictory. The industry has a responsibility to ensure that accurate quality scientific information is made available to ensure that patients have the information they need and can make shared decisions, as Trishna referenced earlier, with their clinicians. The responsibility is to ensure that the information is accessible, so it's ideally not behind paywalls, and that the principles of health literacy are followed and we should be aiming for a reading age of between 11 and 14 to ensure that the information is accessible to non-specialists but also patients and caregivers. Plain language summaries are the most well known avenue for this type of information. But we're seeing the emergence of more novel approaches, including the use of podcasts to share scientific information.

*Adeline 09:51.843:* Thanks, Gavin. Trishna, I wonder if you could please tell us about your various experiences to date of being involved in publication?

*Trishna 10:02.101:* Goodness, where do I start? Some of the things that I've done in this space have included co-authoring manuscripts and posters, abstracts, conference presentations. You can find me on ORCID. If you'd like to see the variety of different topics that I've published on, just search for me on ORCID. It's all there.

I'm also an experienced reviewer of all types of plain language summaries, which Gavin just mentioned. This includes different formats of PLS. You have like the 250 word text only PLS. But you also have plain language summaries of publications and things like infographics, also the lay summaries of clinical trial results that are mandatory in the EU. I've reviewed all of these types of summaries, lay summaries, and I've done this for various different stakeholders. So med comms agencies, directly for sponsors, and also for publishers as well.

Then I'm also the patient lead of Pfizer's Global Publications Collaborative Board. And this is a board that consists of a group of patient advocates and Pfizer publications colleagues. And we provide strategic input into Pfizer's involvement of patients in their publications process. And the patient-centeredness of their publications. This has involved things like creating a patient authorship welcome kit and developing a standard operating procedure for patient involvement in Pfizer sponsored publications. And we're also developing assets that can help Pfizer be more patient-centered in its publications. For example, identifying journals that are more patient-friendly.

And then I've also helped to develop other training and toolkits to support patient involvement in publications. For example, the online PLS training that's available via Karger. I helped to develop the PLS toolkit from Envision the Patient. And I also lead the publication section of the patient engagement module in the Masters in Medical Affairs at King's College London. Now that already sounds a lot, but that's not all. I'm also sitting on various editorial and advisory boards for journals and publishers. I'm a patient reviewer for the BMJ. And I was also a previous patient engagement editor for DIA Global Forum Magazine. And then bringing things back to ISMPP, I was on the former Advocacy and Outreach Committee, helping ISMPP to develop relationships with patient advocacy groups. And I'm now a member of ISMPP's Patient Engagement Taskforce, and I'm co-leading the Assets Evaluation Workstream. I've also sat on the Planning Committee for ISMPP's European meeting for several years as well. So I think that really shows the sheer variety of opportunities that are available for patient involvement in publications and how it's possible to be involved in all these different ways without having a science degree. Because I don't have a science degree. I gave up science after the age of 16.

I think it really demonstrates that there is a willingness and there is an appetite by different stakeholders, including med comms agencies, sponsors, CROs, academia, to involve patients

in publications. That appetite and willingness is there. And there is a huge variety of opportunities available.

*Adeline 14:20.592:* Definitely, and that really is a substantial resume you've got there. How have you found being involved in all of that?

*Trishna 14:32.078:* Well, first off, it's been a steep learning curve, I won't lie. A lot of it has been learning as I go along, asking a lot of questions, doing background reading and self-study. When I started out as a patient advocate, I had no idea what GPP was or the ICMJE or even ISMPP for that matter. And I think it's great that there's now more training out there for patients. So, for example, you have the WECAN and Envision patient authorship training. It was greatly needed. I think that learning as you go along is obviously, you know, it can be done, but it's not necessarily ideal. It's great to have some support and training and guidance, which is now becoming available for patient advocates who do want to get involved in publications. I think it's also been important that I've had to become comfortable with not knowing everything and feeling secure that when I had to ask questions that I didn't look silly and that what I could bring to the table was as valuable as anybody else.

I will say, though, that we are, and I think there is a case for us still working within a system that hasn't yet been optimized for patient involvement. It's still a new area for many organizations, and they sometimes just don't know how to approach things, particularly from a compliance point of view, if we're talking about pharma. There's still a need for more frameworks, more guidance. There's still a need for standards that can provide that guidance, that handholding, which will make involving patients much easier.

I have to say though, and I don't know whether you can feel it coming through the speakers or through the podcast, all of this has been just so rewarding. I've learned lots, I've developed my writing and reviewing and other skills which I already had, but I didn't have the opportunity to develop them further and in different ways. And also, more importantly, I feel like I'm part of pushing the industry forward into new realms. I'm pushing the industry forward out of its comfort zone. And that's something that I just, I love doing. I love a challenge.

*Adeline 17:20.004:* That's fantastic. So, Gavin, if we can come back to you for the med comms perspective, when and how do we involve patients in publications?

*Gavin 17:33.730:* Well, Trishna's given us an amazing compendium of potential activities where patients can really add value. I'm going to boil it down to three specific ways that we've identified within our white paper. And the first of those is within publications planning. This is where patients could sit on advisory or steering groups at a very early stage of development. Incorporating the patient voice early can help researchers identify priorities for research and design studies relevant to patients' lived experience, including meaningful outcomes.

Beyond that, engaging with patients on publication steering committees can help the wider publication team and authors understand patient social reality, including their attitudes, beliefs, and motivations. Patients' perspectives can help the team plan manuscripts that center on patient voices, and identify other types of publications relevant to patient communication.

And then secondly, authorship and publications review. As Trishna says, she's been involved in numerous of these types of activities, and we should continue to strive to include patients as authors wherever appropriate. Patient authorship requires both adherence to, say, GPP guidance as it relates to authorship, and a level of pragmatism within the professional

publications community regarding realistic expectations of patient authors.

I think for me, you know, early engagement is so important and a very early engagement with the patient to understand whether they will meet all the criteria necessary for authorship. So guidelines for authorship should be carefully considered and ICMJE guidance related to those criteria should be reviewed and discussed with patients involved in the publication at a very early stage.

*Adeline 19:30.835:* What can we do if patient co-authorship is not possible?

*Gavin 19:38.244:* Well, if it's not possible, there may be other ways patients can add value, including review of PLS and providing patient perspective commentaries alongside a publication. And again, Trishna has lots of experience and has provided so much value in these areas.

And then finally, in terms of those three areas of patient involvement, participation in the development of post-publication communications, including co-development of infographics and other mediums to help scientific information be more accessible and understandable, and also involvement in other audio formats of information dissemination, like the podcast reference earlier.

*Adeline 20:23.087:* Well, you'll be glad to know I've only got one question left. I'd like to know about what you think the future looks like for patient involvement in publications. Trishna, would you like to take that first?

*Trishna 20:35.121:* This is a really great question, because I think the future looks really exciting. And I'm very optimistic. People who know me know that I am a bit of an optimist anyway. But I will reiterate that we're just not yet working within an environment or system, for want of a better expression, that is optimized for patient involvement. So whilst yes, I'm optimistic, there's lots that we still need to do.

Firstly, we need measurements of the impact of patient-centric publications. I know that this can be difficult, but demonstrating the value will be key to sustainability and organizations continuing to involve patients. And we don't just need to measure the impact. We also need to publish about it. We need to share it so that people can see and organizations can see that there is evidence for the value of involving patients in their work.

Then we also need to ensure that there's diversity and equity when it comes to patient involvement in publications. So in patient authorship, we've actually seen that there's a reversal of the traditional bias towards males, where amongst patient authors, we actually see more females being authors, and that's great. But patient authors generally publish in English and they're from high-income countries, so we need to address how to get patients from all backgrounds involved.

Then we also need to optimize the system for patient collaboration. We need more flexible ways of working, consistent policies around remuneration, which Gavin's already talked about. We need to look at language and accessibility. We need clearer guidance specifically for pharmaceutical interactions in publications. So, for instance, the PMCPA's social media guidance in the UK created a lot of questions that still haven't really been addressed. I'd also love to see a patient author in the next iteration of GPP. I'd be happy to put my name into the mix! But I think we really need to have patients really involved in the development of these standards and these

guidelines.

We need to have continued development of training and support as well. I'd also like to say that organizations can be more active in involving patients. If you're asked to speak about this topic at a conference, for instance, insist that you do it with a patient advocate. If you're creating a publication plan, be intentional in identifying how and where patients could be involved. Be the champion within your organization.

But having said all of the things that I think we still need to do, I do think the future is looking bright. There's so much interest in this topic and so much willingness to develop this area. And I'm really looking forward to seeing how things develop and being a part of this and moving forward and hopefully seeing a lot more change in the way that industry is and other stakeholders are working with patients to get them involved in the publication space.

*Adeline 24:29.245:* Really valid points. Gavin, do you have anything that you'd like to add to that?

*Gavin 24:38.098:* Well, I just completely agree with Trishna's points. I think measuring impact is critical. Increasing guidance and involvement of patients in the development of that guidance as well is essential. It's a really exciting time for greater collaboration between publication professionals and patient communities. And I think its value will grow and grow.

Patient communities are more mobilized and equipped to provide valuable insight and we must meet this with engagement that is led by people who are specialized in this. Trishna made a really strong point around uncertainty with compliance and I think that is solved in two ways. Firstly, more guidance, so you get greater confidence in processes, but involving experts that engage patient communities day in, day out, is essential because they really understand the compliance regulations. They understand how to build thoughtful relationships with patient communities. I think we should approach collaboration with appropriate guardrails, but as important is that we approach it with thought, transparency and empathy.

*Adeline 25:52.550:* Thank you Gavin and Trishna. This has been a very interesting conversation, but we are out of time for today. Thanks for listening to InformED for medical communication professionals. Please take a minute to subscribe to the show on your favorite podcast app, inform your colleagues and rate our show highly if you liked what you heard today. Join ISMPP today to become a part of our community, to participate in our webinars and to receive instant access to exclusive tools and resources. If you're interested, just go to [ismpp.org](http://ismpp.org), that's I-S-M-P-P dot org to learn more. I'm Adeline Rosenberg.