RAW-INF_2023.08.18_Avishek, Catherine, Jonathan

Speakers: Jonathan Patience, Avishek Pal, & Catherine Skobe

Jonathan Patience (00:00):

Hello, and welcome to InformED, a podcast series where you'll 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 SciCom.

Jonathan Patience (00:12):

My name is Jonathan Patience, and I'm Head of Publication Development at Taylor & Francis. My background is in the editorial side of medical publishing, and I've been involved in initiatives looking at how to better engage non-specialist audiences with published research.

Jonathan Patience (00:26):

I'll be your guest host for today's episode, discussing the important aspects for pharmaceutical companies to consider when seeking to engage with patients in the scientific publication process. My guests today are Katherine Skobe, Senior Director Publications, Innovative Solutions Lead at Pfizer and Avishek Pal, Global Medical Director, Cell and Gene Therapies at Novartis.

Jonathan Patience (00:45):

The opinions shared by the presenters today are our own and do not represent those of our employers. Welcome Catherine and Avishek, thank you for joining me. To get started, please could you tell us a little bit about your current roles and what types of patient engagement initiatives you've been involved in? Avishek, I'll come to you first.

Avishek Pal (01:04):

Thank you, Jonathan, it's a pleasure to be here. Well, I've been in traditionally scientific communication roles for the last 15 years, and earlier this year, I transferred into a pure medical role, global medical role in cell and gene at Novartis.

Avishek Pal (01:21):

Primarily, looking into scientific engagement and strategy, looking into, of course, key markets providing medical leadership. And as you know, this topic is very close to my heart. In the past, I've been involved in a lot of these plain language summary standard development initiatives, like the one from PFMD, from the one from ISMPP.

Avishek Pal (01:47):

And then of course, when Novartis started this journey a few years ago, I led the development of our plain language summary toolkit, which in a way standardized how

we do things within the organization. So, thank you for having me, looking forward to today's discussion.

Jonathan Patience (02:07):

Great, thanks Avishek, sounds like that is something you're really passionate about. So, Catherine, could I come to you next?

Catherine Skobe (02:13):

Sure, thank you, thanks for having me. I have been co-leading the publications management team at Pfizer for a while, and my current role is around innovative solutions and publications, and so that extends to working with patients.

Catherine Skobe (02:30):

And more recently, some of the work that we've been doing has been the formation of a collaborative board that is comprised of eight-patient advocates in various therapeutic areas, because the intent is really to learn more about how we can do better in publications from their perspective.

Catherine Skobe (02:52):

Some other initiatives that we have that are more patient-oriented, of course, are around pushing open access publishing, and making sure that we try to make our publications and content as accessible as it can be. We've been working with journal publishers such as yourself at Taylor & Francis around trying to find homes for this information and content, and trying to understand what are the barriers that they face and how can we overcome those together.

Catherine Skobe (03:22):

And then lastly, really, just looking at baseline measurements. Where are we today in open access publishing? Where are we with patient authorship, so that we can continuously hold ourselves accountable for making sure that we are trying to progress these initiatives within the organization, and understanding where we came from and where we're going. So, that's it in a nutshell.

Jonathan Patience (03:52):

Brilliant. Well, it sounds like between the two of you, it sounds like we've got a great range of experience to come to this discussion with. So, I'm sure we'll be able to come out of it with some great practical tips for anyone else out looking to follow similar paths.

Jonathan Patience (04:06):

So, why do you feel that patient engagement in publications is valuable? Catherine, could I come to you first?

Catherine Skobe (04:15):

Oh, sure, absolutely. So, obviously, I mean, obvious to me, ultimately, patients are our primary customers. That's the whole intent of the pharmaceutical industry, serving patients and trying to support them in increasing and improving their healthcare.

Catherine Skobe (04:33):

And so, specifically, the publications; the data, the research, the content that we're developing is really to help improve patient outcomes. And I think it's important, as I mentioned earlier, that we need to understand from their perspective why and how we can communicate better by engaging with them.

Jonathan Patience (05:01):

Yeah, it sounds like something that you're very passionate about too, and I think it's great to see that shine through. And Avishek, how about you?

Avishek Pal (05:13):

I think Catherine captured it really nicely. I feel like we have crossed that stage where publications are purely intended for a scientifically trained audience. So, as we expand our target audience through our publications, I think it's only fair that we involve them in the development of these and essentially, to bring their voice in the development of these kinds of initiatives.

Avishek Pal (05:43):

It allows us to enable the kind of perspectives they bring in, they can talk to us about their relevance, they can talk to us about the utility. So, in a way, they shape the content and they shape the material in a way that can be of benefit for them at the end.

Avishek Pal (06:07):

And at the end of the day, this is also, I feel, a way to acknowledge their contributions and their benevolence in terms of how they have been very generous with their time and their effort in sharing with the scientific community their experiences. So, I think it's fair to have them there, it's a crucial piece in the knowledge transfer process.

Jonathan Patience (06:30):

Yeah, it feels like a really natural evolution of the way things are going, and it's great to see the two of you sort of pioneering in that area. I think it really chimes with my own experiences from a publisher perspective because it seems like the world is increasingly overcome by misinformation and we're finding that patients are more directly going towards academic sources.

Jonathan Patience (06:55):

And so, I think it's important that we have some sort of plain language outputs that communicate trusted research in a more digestible way. So, thinking about people who would want to partner with patients in publications but don't know where to start, what would be your tips on the first steps to take? Avishek, I'll come to you first.

Avishek Pal (07:22):

Well, thanks Jonathan, for this very important question because there's so much that one can do, and I think it's only fair to get lost in this whole gamut of activities.

Avishek Pal (07:31):

From my point of view, I think what's important is to have that alignment on purpose and objective upfront, the cross-functional team; what is it that we are trying to do? Why are we trying to do it? What would success mean for the whole team? And I think that will set the tone for the next steps.

Avishek Pal (07:52):

And then of course, you have in terms of partnership, really it's crucial to identify who could be advocates internally who could actually have similar values like for this initiative, who could have common purpose like this initiative, and then bring them all together, and that's how the cross-functional team comes together.

Avishek Pal (08:18):

Because that's super important when it comes down to execution so that you don't have to reinvent the wheel. For example, there could be a small group within the organization which has some mechanism in place to partner with patients, and you don't have to start from scratch. Maybe there are rules and regulations that they have come up with, they have fought the battle for you, so why not just get them on board and try to work through that situation.

Avishek Pal (08:43):

And then, of course, looking at educating the stakeholders for those who are not part of the initiative directly. I think it's very important to take them along with you because then, at the end of the day, when we are evaluating success, it's very important that they understand what the purpose was and what the objectives were, and what we achieved.

Avishek Pal (09:05):

And then finally, I would say seeking external validation and input, I think that's super critical. Sometimes we are sitting in an eco-chamber, we are talking to each other, we feel like we are doing a great job, our audience understands what we are doing, but perhaps not.

Avishek Pal (09:22):

So, maybe it's a time to also get some outside-in viewpoint to really understand, are we doing what we are doing correctly, so these are my few points.

Avishek Pal (09:31):

Like I said, Jonathan, I'm a bullet points person, so perhaps the top three or four things from me. And perhaps Catherine can add more because she, as part of Pfizer, has been doing a phenomenal job trying to bring more of these initiatives to the forefront.

Catherine Skobe (09:46):

Well, thank you for that segue, Avishek. I think I'm just going to pick up from where you left off. I loved your important points that you've shared with all of us. I think picking up from there, as you are aware, we, as I mentioned earlier, have our collaborative board with patient advocates. And so, we started by looking and really trying to hear from the voice of the patient.

Catherine Skobe (10:13):

We hosted an advisory board a few years ago where we selected patient advocates, and I can get into that in a little bit to really hear from them and learn from them where we can improve our practices and get them actually involved in the publication process, what the ultimate goal is having them involved from the end-to-end publication process.

Catherine Skobe (10:36):

From there, during that advisory board, we had a patient preference survey. We asked them about the types of formats they prefer, and of course, it varies depending on the situation, and which audience you are engaging with.

Catherine Skobe (10:55):

But what we decided was this is actually not a onetime thing; it should really be a longer-term initiative because we have so much to learn from them. So, that's how our collaborative board formed. We currently have eight patient advocates who are involved. And have developed a three-year strategic plan where we have a longer-term vision of what we want to achieve together, which has been great.

Catherine Skobe (11:25):

We're looking at a host of things like authorship pledges where we are sharing our commitment to involving patients in publications. We're looking at presentations where we can externally and internally share the importance of having that patient voice because that's adding to that diversity that's required, that even HCPs should hear from them as to what their experience has been.

Catherine Skobe (12:00):

We want to maintain a longer-term relationship with these patient advocates so that as the space evolves, we can have them shape the work that we're doing. And often what

I'm asked about is maybe in an organization not quite as large as Pfizer, how can other companies do something similar?

Catherine Skobe (12:23):

My suggestion has always been surveying a patient advocate or several and get their input. I mean, just at least one time to see if you're on the right track. And then working with your patient advocacy partners as you've suggested Avishek, and seeing where you can tap into their resources to help you identify what their involvement could be in your work. So, I don't know, Jonathan, I think I'll pass it back to you now.

Jonathan Patience (13:00):

Brilliant, thank you both for those really useful and practical tips. I can see a couple of themes coming through, especially with the obtaining of internal stakeholder inputs and making sure that everyone who needs to be on board is on board, but also the external stakeholders.

Jonathan Patience (13:18):

And it's interesting to see that actually you can get patients engaged from square one really by reaching out to them, finding out how they feel about the way you're currently approaching things and what your plans are so that's great.

Jonathan Patience (13:33):

So, how would you identify the right people to take part? Catherine, I'll come to you first.

Catherine Skobe (13:41):

Sure, I can explain how our collaborative board was formed, because I think that would probably resonate with most people in that, as Avishek also mentioned earlier, is tapping into those who work most closely with patients.

Catherine Skobe (13:58):

Within our organization, we obviously have patient advocacy colleagues, and so we reached out to them across various therapeutic areas to identify advocates that they thought would be interested in doing this type of work.

Catherine Skobe (14:17):

We invited a few of them and then through our own, the publications management team, as we've been involved with DIA and ISMPP and other organizations, we met a couple of patient advocates from there. We formed our basic smaller group initially, and then we took a look at the membership, and we really wanted to make sure we had diverse representation.

Catherine Skobe (14:43):

We noticed that there were certain gaps that we wanted to fill, and then those initial members identified people that they knew from their network. So, we were able to bring in other patient advocates from different parts of the country who represented different affiliations, and so that was really nice.

Catherine Skobe (15:10):

We have a very nice mix, and we also understand where our current gaps are so that in the future, if we decide or when we decide to expand, we know where the gaps are that we want to fill.

Catherine Skobe (15:23):

I think using a couple of different ways to get to forming that group is one nice way to approach putting together a collaborative board. I think that's the best advice I have to offer on that. Avishek I'm sure you probably have a different experience.

Avishek Pal (15:49):

No, you covered it beautifully, Catherine. And I think at the risk of sounding like a broken record, I have to say, I think leveraging existing internal experts, those, like you mentioned, closest to patient advocacy or engagement, definitely is a time saver, is more efficient. Also, they bring in a lot of these already existing patient experts and panelists who we can leverage on.

Avishek Pal (16:19):

From my experience also, conferences have played a crucial role in our case where we have these additional engagements with patient organizations directly, and then some of them are interested in partnering with us on these kinds of initiatives and activities. And then we count on them to make recommendations on who could be partners with us in such activities. So, absolutely, internally and externally, again, identifying these like-minded folks, super important.

Jonathan Patience (16:51):

It sounds like things can really snowball once you get the ball rolling on this. And once you get the people involved who are really passionate about this, then they can connect you to the right people and they connect you to more people, and then it grows into a great initiative. So it's great to hear about your experiences on it.

Jonathan Patience (17:09):

And how about barriers? Have you encountered many barriers on this kind of road to setting up patient engagement in this way? Avishek, do you have any thoughts on that?

Avishek Pal (17:25):

I could write a book but I'm going to restrict myself today to maybe a few top things. And again, none of these are absolute barriers, they can easily be worked around. The

first thing definitely is the industry, there's always a perception of wrongdoing, always a perception of off-label promotions. We need to be doubly cautious about how we approach this.

Avishek Pal (17:57):

And I think this is something that always is challenging in a cross-functional setup where we have colleagues from geographies that are different in terms of legal and compliance setups. So, I think that's definitely one barrier that definitely needs discussion, upfront discussion before we even get started on such kind of initiatives with patients.

Avishek Pal (18:20):

And of course, alongside that, the whole question and ongoing debate on remuneration of patients for their time, and especially if it's authorship and publications, how does that board in terms of ICMJ criteria, GPP and whatnot. So, again, that's something that's a completely different discussion.

Avishek Pal (18:40):

The other aspect, which I have often felt could be a challenge, is the question of how do we measure the success that we spend on such activities? So, that is something, again, worth looking into up front. And then again, are we in a position to really measure tangible benefits from these kinds of initiatives? And is it even the purpose of such initiatives? So, these kinds of questions and discussions come up oftentimes.

Avishek Pal (19:17):

And then of course, I've always struggled with this one, which is, who's the true voice of patients? Is it the patients themselves? Are the patient advocates? Is it the patient advocacy organizations? How do they all sum up? And who's the right or appropriate representative when it comes to these efforts?

Avishek Pal (19:39):

And I would say, the next one would be how do we standardize what we do across the organization by different teams, different therapy areas, different regional global teams, how do we optimize the standards, the templates, the processes without reinventing the wheel every time?

Avishek Pal (19:59):

And the final one, the final one is definitely the budget and effort. And that's why I mentioned previously, when we were discussing the other question about starting up always to know what the purpose is and what the objectives are, and what the success measures is.

Avishek Pal (20:16):

So, the cost and the budget requirement would come in based on those, and I think that could be a challenge. It's probably not as easy to procure budget and easy to prepare these materials or involve patients as we think it is. So, I think these are, I would say, my top five and maybe Catherine could add a few more on this.

Catherine Skobe (20:37):

So, maybe I could just briefly add. I mean, I think you hit the nail on the head around budget, and that's how, by bringing in at least a small handful of patient advocates to hear from them helps validate the need for including them in the process, which I think helps the buy-up of that within an organization, and getting the leadership to understand why there's a clear need for this.

Catherine Skobe (21:06):

I think the other barrier for us really has been finding the right homes for this content. And that's why working with our publisher friends is really important to help convey the importance of finding a trusted peer reviewed source that we can create all of this content, but realistically, I think people want to hear it from a trusted source of information. And so, knowing that it's been peer reviewed and coming through a legitimate publisher is an important piece of the whole process.

Jonathan Patience (21:49):

So, it sounds like it's certainly not an easy route, but it's a route that you can usually find solutions to throughout the work. And I think from learning your experiences hopefully we can identify those in advance. I think what you've said about getting internal stakeholder input from the beginning, it sounds like that's a really key aspect, especially helping with things like standardization and budget and efforts, so it is really great to have your experiences on that.

Jonathan Patience (22:22):

So, finally, we're coming to the end of the podcast now, so if you could leave our listeners with one key takeaway to guide them in engaging with patients for their publications, what would it be? Avishek, I'll come to you first.

Avishek Pal (22:41):

Super. And Jonathan, it's been a pleasure. I think such important points, and again, with someone like Catherine on the line, you on the line from the publisher's side, I think this has been fantastic. I'm a man of many words, not few words, so I'm going to try and be as succinct as possible.

Avishek Pal (23:00):

I think it's an ethical obligation, I think it's a moral obligation now to involve patients when it comes to publication development. It is super challenging to execute, but again, when we see the outcomes, it's immensely gratifying. So, being inclusive, enabling

partnership, I feel these are the only ways we can responsibly improve public engagement in science. So, for me, I think that's the takeaway.

Jonathan Patience (23:29):

Great, thank you Avishek and Catherine?

Catherine Skobe (23:31):

Well, that was great Avishek, I mean, I'd have to echo that. And Jonathan, I have two points, so I couldn't limit myself to just one. I think embracing, encouraging companies to have outreach to patients, getting them involved - I think listening to the patient and having them help determine the gaps in your process is only going to make it better. And ultimately, it helps meet their needs because that's the end game here.

Catherine Skobe (24:03):

And then one thing I have not emphasized enough during our conversation is really about accessibility and open access publishing. I continue to talk about over and over again, is really how do we overcome this barrier for anyone to have access to all of this incredible content and research that we spend lots of time and resources in developing.

Catherine Skobe (24:31):

And so, I think we cannot underestimate the need to make sure that our content is available to anyone. So, those are my parting words, and it's been a pleasure. Thank you, I really appreciate having this conversation with both you and Avishek. I think it's really important in the work that we're doing.

Jonathan Patience (24:56):

Two really important points there from you, Catherine, so I'm happy to let you get away with listing two. Thank you both, it looks like we are just about out of time. I'm sure we could then spend far longer on this topic. And it would be fascinating to delve further into those barriers or to speculate on other subjects like what role AI might have in supporting some of these initiatives in the future.

Jonathan Patience (25:20):

For example, using large language models to translate research into plain language, which is already undergoing some experimentation, albeit with much needed caution. But that's all we have time for today.

Jonathan Patience (25:33):

Thank you, Catherine, and Avishek for joining me and sharing your experiences. I think our listeners will have some great practical tips on how to get started.

Jonathan Patience (25:41):

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.

Jonathan Patience (25:54):

We hope you'll also join us at an upcoming ISMPP U Webinar or even consider becoming a member of our association. Just go to ismpp.org, to learn more. I'm Jonathan Patience, thank you.