

## **RAW-INF\_2023.09.12\_Jacqui, Kelly, and Sarah**

Speakers: Kelly Soldavin, Jacqui Oliver, & Sarah Griffiths

**Kelly Soldavin (00:00):**

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.

**Kelly Soldavin (00:09):**

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**Kelly Soldavin (00:22):**

My name is Kelly Soldavin, and I'm a Senior Editor with the publisher, Taylor & Francis, and also a patient with a chronic disease, which makes me particularly passionate about amplifying patient voices. I will be your guest host for today's episode discussing how you, our listeners, can partner with patients throughout the publication process.

**Kelly Soldavin (00:41):**

My guests today are two people that share my passion for patient engagement, not to mention, they're experts in this area. Jacqui Oliver and Sarah Griffiths, thank you both for joining me.

**Kelly Soldavin (00:53):**

To get us started, Jacqui, can you tell our listeners about your current role and its connection to patient initiatives?

**Jacqui Oliver (01:07):**

Hi, yes. I'm Jacqui Oliver and I'm a Scientific Director in the Envision the Patient team, which is a specialist team within Envision Pharma Group.

**Jacqui Oliver (01:14):**

A lot of our work involves involving patients throughout the publication lifecycle, so that might be looking at publication planning, being part of a publication steering committee, collating patient insights for publications, and then actually involving those patients as co-authors on those publications, and then right through to disseminating publications. And that includes reviewing and developing plain language summaries.

**Kelly Soldavin (01:40):**

Thank you so much. And Sarah, we'd love to hear from you about your role and the patient initiatives you've been pursuing.

**Sarah Griffiths (01:47):**

Brilliant. Great. Hello everybody, my name is Sarah Griffiths and I lead the Patient Engagement and Policy team at Oxford PharmaGenesis. And similar to Jacqui really, we work with different pharma

clients and patients and patient advocacy groups, and that's throughout the drug development continuum.

**Sarah Griffiths (02:02):**

And in the publication space in particular this includes working with patient authors and reviewers' health literacy training and guidance, and also, plain language summaries.

**Kelly Soldavin (02:14):**

Thank you, Sarah. So, I'm going to jump right in here with some questions for you. Well, the first one is, why do you feel that including the patient voice in publications is valuable? I'm going to ask Jacqui to start first on that one.

**Jacqui Oliver (02:28):**

Okay, thanks Kelly. Well, I feel that patients and caregivers have really valuable and unique insights that they can bring to publications. And that's sharing their experience of living with a condition on a day-to-day basis, rather than getting a healthcare professional to input and provide their views on what it's like to live with a condition when they only see that person on a week-to-week basis. So, they really bring different viewpoints into publications that might not have been considered previously.

**Jacqui Oliver (02:58):**

And actually, it really helps to improve understanding of the lived experience and identify unmet needs, for example, about improving patient care or possible new treatments. You know, what are the new treatments that patients actually want and will use. So, it can actually help improve trust as well as research results, ensuring that those publications are relevant and actually understandable to a wider audience.

**Jacqui Oliver (03:23):**

And we know that involving patients, the value is increasingly recognized, not only from major funders — from publishers as well, we're seeing more different types of articles that patients can get involved in, and we're seeing that increase in patient authorship in peer-reviewed publications. But what we also know is that people really do need more guidance on how to work with patients in publications.

**Kelly Soldavin (03:50):**

Yes, that's so true and that's why we're here today to talk about how people can practically move forward with involving patients and involving the patient voice. So, Sarah, can you speak a little bit about the value of including patients in publications?

**Sarah Griffiths (04:06):**

I think Jacqui's covered loads of it. It's so important I think particularly for — you want to challenge assumptions. People go through life, and they read the medical literature, whether you are an HCP, an expert in the field or newly exploring it, you are a medical writer, a pub specialist, whatever. You kind of have your assumptions potentially about what it's like as a patient, but hearing it directly is super powerful.

**Sarah Griffiths (04:29):**

It also uncovers some issues that people probably — you don't know what you don't know. And historically, medicine and pharma are very top down, and it's for patients, that's ultimately what this is all for. So, capturing their voice, hearing what they have to say, I think can only help benefit the equality, diversity, inclusion, and accessibility of medical research and literature to a broader audience. So, it's one step to doing that.

**Kelly Soldavin (04:58):**

I really like that point about how the patient voice also captures that whole initiative of DEI, which is diversity, equality, and inclusion.

**Kelly Soldavin (05:06):**

And Sarah, I was going to ask you, what are some of the first steps people should take if they want to start including the patient voice? We talk about doing it, but what are some first steps they can take?

**Sarah Griffiths (05:19):**

Well, I'd say we're all of us researchers, do your research, there is a heap of information out there. The latest GPP has got some good useful information out there, but there's other resources out there that are in the public domain, I think Jacqui's going to talk to those a little later.

**Sarah Griffiths (05:34):**

But also within companies and groups, no matter your size, there's highly likely to be people in your company who've either done this before, or who could point you in the right direction. Whether it's the publications leads or a global or local level, your patient advocacy team leads within marketing or commercial — do reach out, network, ask, even ask your agencies as well.

**Sarah Griffiths (05:55):**

If you're working with different agencies, it is highly likely they've got some experience of the dos and don'ts of working with patients. They're often the ones who are interacting more directly with the patients as well, and be open-minded and don't be scared, just ask.

**Sarah Griffiths (06:16):**

And it may be that the time isn't quite right for what you would like to do with ... You must think about the right project at the right time, but do your groundwork, do your research, spend a bit of time, don't go in there with heavy boots because it's delicate, you need to treat people carefully. But hopefully, the rewards will be worth it if you go about it in the right way.

**Kelly Soldavin (06:39):**

Absolutely, I think the rewards will absolutely be worth it. Jacqui, Sarah mentioned it's about identifying people to work with. How do you identify the right people to work with on these types of projects of getting the patient voice involved?

**Jacqui Oliver (06:54):**

That's a really good point. What Sarah mentioned there was like thinking head and not rushing into a project. And it's very important to think about what type of patient do you want for the project. Do you want someone who's going to provide their kind of personal perspectives on what it's like to live with a

condition? Or do you want the wider viewpoint from a patient expert or a patient advocate who can help kind of represent that wider patient community? So, I think that's a really good starting point. Think about the right person for the right role as well as which project you're working on.

**Jacqui Oliver (07:26):**

And caregivers can be an option as well. It's not just a patient because if you are a caregiver for a young person living with a condition, you could involve those in the project as well. Or equally for older people or someone who's not well enough to provide their personal insights, that caregiver role — caregiver insights are important as well.

**Kelly Soldavin (07:48):**

Yes-

**Jacqui Oliver (07:48):**

So, when you're thinking about ... oh go on sorry.

**Kelly Soldavin (07:51):**

No, no, go ahead, I was just completely agreeing with you.

**Jacqui Oliver (07:54):**

So, you kind of thought, "I know what type of patient I want to involve on this, so how do I actually start?" And I think that personal recommendation is a really good starting point and Sarah just covered that a little bit.

**Jacqui Oliver (08:07):**

So, ask people that you work with, are there any patients they already work with? Are there any patient councils within your group that you can help identify a patient who wants to be involved as well, wants to put their voice into publications?

**Jacqui Oliver (08:22):**

Because you've got to have someone who is willing to invest the time and is interested in being involved in the project and understands what's going to be involved, and what time commitments are involved as well.

**Jacqui Oliver (08:36):**

So, moving on from recommendations, we are increasingly seeing patients being involved at major conferences or involved in webinars. And we saw a lot of that at the [Annual 2023] ISMPP meeting, at the Patient's First meeting, it was great. Patients were on round tables, they were on the podium presenting abstracts.

**Jacqui Oliver (08:56):**

So, look for those types of patients as well because you know that they're interested in getting their voice into the peer review publication. So, that's a really good way to look for patients as well.

**Jacqui Oliver (09:09):**

If you are interested in having a patient author on a publication, one way to try and identify that type of person is to look in PubMed and you can identify patient authors because some people now will have that as an affiliation. So, you can search PubMed by just searching for patient author or caregiver author.

**Jacqui Oliver (09:36):**

There isn't yet a consensus on what term should be used or what affiliation and it would be great to get some kind of consensus on that from the wider community because we know that's a bit of a sticking point, not all patients want to be known as a patient author. So, we need the conversation to be moving on that.

**Jacqui Oliver (09:54):**

But it is a good way of identifying possible patient authors. But I would say that would be an experienced patient author. There are loads of resources out there now that can help less experienced patient authors to be involved as well. So, it doesn't have to be someone who's already published, it's really good to get other people involved as well.

**Jacqui Oliver (10:18):**

And thinking about it from wider channels as well, you could look at patient advocacy groups, you could look at social media patient engagement vendors — there are many different channels, but I would say try and think about the right person for the right role. So, hope that helps.

**Kelly Soldavin (10:37):**

Oh, that's absolutely incredibly helpful. Of course, every project or initiative doesn't always run perfectly. So, what are some of the barriers that you've encountered during the process of bringing the patient voice in or working on a patient engagement initiative? Sarah, can you talk to us a little bit about that, and then I'll switch over to you, Jacqui?

**Sarah Griffiths (11:01):**

I think the challenges can vary at different points along the process, whether from right at the beginning to the end.

**Sarah Griffiths (11:11):**

But I think one of the key things that you could do is part of the planning, because say if you're thinking right at the beginning when it comes to publication planning, there have been some people say, "Oh, cherry picking," or would we want to just involve a patient on a phase three clinical study, which it wouldn't be appropriate to, for instance, and there's a bit of nervousness potentially around it.

**Sarah Griffiths (11:36):**

So, when I've spoken to Pubs leads and ISMPP and the conversations that we've had there, people are like, "Oh, I'm a bit apprehensive about this, it might not be compliant." Speak to compliance people early, get it part of your publication planning, so that it isn't cherry picked because it won't always be appropriate to include a patient in a publication as an author or a reviewer. It ties in with what Jackie said, it's part of the planning, the right patient, and it's for the right project as well, so that's a common one.

**Sarah Griffiths (12:07):**

The other one as well is really thinking carefully about your target journal. Some are going to be more receptive to patient authors than others and I know we always talk about this when we speak with publishers, it's a really easy thing to do, is just contact the editors, see what their appetite is.

**Sarah Griffiths (12:26):**

Inherently, there's going to be some publishers who are more eager to involve patient authors, more receptive to it and they really see the value of it. And others, it might be new for them, but just communicate with them. And to that point, I spoke about this at ISMPP in the Annual Meeting - language. Language for me is a massive thing. We're all communicators but we forget who we're communicating to and with.

**Sarah Griffiths (12:53):**

We're all very well-educated people, and we use acronyms left, right, and center and it can be impenetrable to people. So, when you're communicating with patients, no matter who... Be clear, be friendly, be appropriate, and don't litter your emails or communications with a load of mumbo jumbo jargon acronyms, because not everyone will feel comfortable in challenging you.

**Sarah Griffiths (13:21):**

I know some are ... a few have asked me, "What does HCP mean? What does PLS mean?" Spell it out, it isn't always familiar, and we often forget that, so that would be my advice. And don't underestimate being kind and friendly and empathetic when you're communicating with patients, it goes a long way.

**Kelly Soldavin (13:38):**

Yeah, absolutely. And I love your point as the publisher here bringing up perspective of always reach out to your journal contact or editor, someone you know at the publisher because we are more than happy to talk to you about what we can and cannot do.

**Kelly Soldavin (13:52):**

I can speak on the behalf of Taylor & Francis and many of the people I know at ISMPP that are in publishing that we very much support getting patient authors on board. So, now Jacqui, can you tell us a little bit about some of the barriers you've encountered and how you've overcome them?

**Jacqui Oliver (14:08):**

I just want to pick up on one point that Sarah mentioned then about the kind of jargon that we use. And, you have to be aware that patients, not all patients but some patients may not be familiar with the whole publication process. They might not understand what the peer review process means.

**Jacqui Oliver (14:24):**

One really good way of kind of overcoming that is to provide a clear plain language overview of the steps involved in the publication process that's right through from your initial kickoff calls to submitting it, peer review comments, dissemination of the publication afterwards, so that can really help.

**Jacqui Oliver (14:42):**

And then that would help -having that clear overview as well can help the patient understand what their time commitment is because you do have to take that into consideration as well.

**Jacqui Oliver (14:54):**

I would also recommend having plain language versions of good publication practice guidelines so you know that the patient authors understand their roles and responsibilities and how they can meet authorship for that publication. And plain language versions of authorship agreements or at least an overview of what that authorship agreement means can help as well.

**Jacqui Oliver (15:19):**

And there are lots of training courses as well available for patient authors such as the WECAN patient training course as well that goes kind of through a step by — it's four different modules and it's a step-by-step overview of the different steps involved, and it helps build the confidence of the patient authors. So, definitely, look out there for all those resources.

**Jacqui Oliver (15:42):**

Another thing I see as a barrier is to just be aware that a patient or caregiver may be juggling so many other commitments. They may be attending healthcare appointments or job commitments, just family life in general as well. And I think that's really key to bear that in mind, so be flexible.

**Jacqui Oliver (16:04):**

I'd say that's a really key point over when you're making your timelines for the project, just be aware that when you are arranging meetings, don't do it to fit the company or the publisher or the medical writing team. Think about what time the patient is going to be fitting with their schedule.

**Jacqui Oliver (16:22):**

And be flexible as well because they may not be feeling well and they may not be able to make that meeting. So, building that contingency into the timelines as well and provide that early notice of what the deadlines are. So, just be realistic actually about the timelines that are involved.

**Jacqui Oliver (16:43):**

And one other barrier I think a lot of patients may face and we are very familiar with using all the different kind of Zoom and Teams and all that different software, publication software, but if you're working with patients and caregivers, they may not be familiar with that.

**Jacqui Oliver (17:02):**

So, you need to bear that in mind and think, well, how is the best way to have a chat with them about how they can provide input on these documents? They may prefer to do it just over a phone call or email. Again, it's being flexible, I think that's important. And have an initial call with a patient as well to make sure that they do understand how the software works and it's all working correctly.

**Jacqui Oliver (17:29):**

Because we turn up on these calls and we always have issues, don't we? So, it's nice for them to understand it's not just them that it might not work for, we all have issues with software, but just giving

them the confidence and the familiarity with this software can just help them to really fully participate in the project.

**Jacqui Oliver (17:51):**

And as part of that, my last point would probably be to just have a key point of contact for the patient. So, if they have any questions like, "Oh, the software's not working, or I can't make that meeting," it's just one person that they contact. It's not that they've got to think, "Oh, well who can I contact today to find out the problem to that?" So, I think a key point of contact as well can really facilitate involvement, so that would be another point that I would make.

**Sarah Griffiths (18:19):**

I'd echo that one, Jacqui. I mean, we've found from working with patients that there may be a level of imposter syndrome as well, when they're looking at reviewers' comments, they're like, "But this important doctor has said this and I don't quite agree, how do we manage that?" And it may well be that you need separate meetings with them throughout the process, so their voices are on an equitable platform as some of the medics are.

**Sarah Griffiths (18:47):**

But also, as Jacqui said, being that point of contact and that advocate as such for the patient author is quite important. Whether that's the Pub's lead or the medical writing agency just to help support and guide that person through the whole process is really helpful and definitely worth doing.

**Sarah Griffiths (19:06):**

And, I remembered another barrier — payment, that's always a tricky one. The elephant in the room, I know it, I know there's guidance within GPP and different companies have different approaches to it. It's always worth checking with your own company internally what their approach is to reimbursement of patients.

**Sarah Griffiths (19:30):**

It's an evolving situation and whilst patients may not want to be reimbursed for their time, if they're doing it out of altruistic reasons, always ask. Always ask what their preferences are, ask how they prefer to be reimbursed within the context of knowing what the policies are is what I'd say.

**Kelly Soldavin (19:52):**

And just very quickly before we move on to wrapping up, Jacqui, you mentioned a training program. Was it WECAN, as in W-E-C-A-N? I just want to make sure that our listeners can find it.

**Jacqui Oliver (20:05):**

Yes, it's the WECAN training course. It's free to access set up in four easy to use modules. And it just kind of goes on a step-by-step guide throughout the process. So, I'd really recommend looking at that if you're looking to help provide a training course for patients services for free.

**Kelly Soldavin (20:25):**

Wonderful. Alright, well we're just about out of time. So, I want to ask you one last question before we wrap up today. And that is, if you can leave our listeners with one key takeaway to aid in their engaging



patients or getting the patient voice into their publications, what would that be? And I'm going to go to you, Jacqui, first. What would be your key takeaway?

**Jacqui Oliver (20:46):**

My key takeaway, it would be at the end of the project, don't just assume that the project's gone well, ask the patients how they thought it went. There are patient authorship experience surveys that are available for people to fill in.

**Jacqui Oliver (21:02):**

So, you find out what went well, did they enjoy taking part? What challenges did they face? Because you can't assume that everything has worked, there are likely to have been challenges. And by addressing them, then you improve future collaborations as well.

**Jacqui Oliver (21:20):**

It's not just looking at the publication metrics for a patient authored publication, it's asking the patients about their experience of being involved and what the quality of patient engagement is. So, that would be my key takeaway.

**Kelly Soldavin (21:35):**

Thank you. And Sarah, your takeaway?

**Sarah Griffiths (21:39):**

It's around asking. Again, not so much as asking for the experience, I would ask people who are considering doing this; I'd ask them to put themselves in the shoes of the patient. Always have that in mind. So, that will help guide you in how you communicate, in what you can do to make this a valuable and worthwhile experience for those patients.

**Sarah Griffiths (22:02):**

And tied into what Jacqui said, if patients have a great experience, then they're likely to say, "I had a great experience working with X, Y, Z on this amazing project," and they spread the word. So, it's kind of a win-win situation.

**Sarah Griffiths (22:14):**

And then on the flip side, if it doesn't go so well, then you don't want that news spreading, but it will. So, I just try and be considerate and mindful and empathetic to patients who are giving up their time and energy whilst they're dealing with their own health just to always be mindful of them at the end of the day.

**Kelly Soldavin (22:35):**

Well, I'm going to take this right out of your words Sarah, I've had a fabulous experience today talking to both of you. Thank you so much. Thank you to our listeners for listening to InformED for medical communication professionals.

**Kelly Soldavin (22:49):**

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**Kelly Soldavin** (22:57):

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](http://ismpp.org) to learn more. I'm Kelly Soldavin.