



Plain Language Means Better Science

with

- **Dr. Oleksandr Gorbenko, Ipsen**
- **Adeline Rosenberg, Oxford PharmaGenesis**
- **Joanne Walker, Future Science Group**

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KENNEALLY: Last week, at the European Meeting of the International Society of Medical Publication Professionals, a leading pharmaceutical firm announced a breakthrough dramatically affecting doctors and patients alike. This important research advancement did not occur in any laboratory – it emerged after close examination of the drug company’s communications policy.

Welcome to Velocity of Content. I’m Christopher Kenneally for CCC.

In the lab, Ipsen concentrates its research in three key therapeutic areas: oncology, rare disease and neuroscience. At the writing desk, it is also a leader in making that research widely available. Since 2019, Ipsen has committed to publishing its research exclusively with Open Access journals.

Now, Ipsen has become the first pharmaceutical company to commit to publishing, as a minimum, a 250-word plain language summary alongside all company-sponsored journal publications that include data from human studies. This commitment will apply to articles published from July 2022.

We devote this program to the Ipsen announcement and what it means for patients, publishers and physicians.

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KENNEALLY: Dr. Oleksandr Gorbenko is UK-based global patient-centricity director for Ipsen. Welcome to the program, Dr. Gorbenko.

GORBENKO: Thank you very much. Happy to be here.



KENNEALLY: Well, we look forward to speaking with you about plain-language summaries and really want to start on the back of this news announcement from Ipsen and ask you, why are plain-language summaries so important to the company? How do they fit in to your mission as a drug developer?

GORBENKO: It's a really important question for us, because plain-language summaries contribute to our mission to be a transparent and open company to all our stakeholders, but first and foremost, for patients, for caregivers, and for any members of patient communities.

So definitely, plain-language summaries contribute to transparency and increase the literacy of members of patient communities, of course, and also provide some critically important information for patients and former study participants, for example. If they took part in a study, of course it's interesting for them to know what we have – what the results are. And exactly it's our mission – it's our strong strategic pillar.

KENNEALLY: You began to tell us a bit about who benefits from plain-language summaries. There are the patients who are involved in the clinical trials, but there are many other groups as well. Can you help us understand the range of stakeholders here?

GORBENKO: We need to have two main groups here. The first group – it's a more narrow group, but it's the group of study participants. If we had, for example, a Phase 3 clinical study with 1,000 participants, first of all, we need to share results and share what we achieved – what we had in terms of patient-reported outcomes, primary and secondary endpoints with them.

Second huge group is the global community – global community, let's say, English-speaking or if we're able to translate for any other broader community of people. Because it's access to science.

KENNEALLY: Well, the point of accessibility for patients is really highlighted today by, of course, the global pandemic, the COVID-19 global pandemic. We've seen that scientists, medical researchers, and pharmaceutical companies understand more than ever that they have to address the public's questions and concerns about their work. So do you think that plain-language summaries can help close the credibility gap that has opened up between scientists like yourself and the general public?

GORBENKO: By my experience over the last two years, not even plain-language summaries, but general medical information inquiries increased significantly over the first months of the pandemic. Because patients had big concerns with medical appointments, with hospitals, with chronic debilitating conditions, with cancers, and some delayed



appointments and something else. So patients tried to find some information and called to medical information of the biggest pharmaceutical companies, including Ipsen. Our medical information department, I should say, was the forefront of – these people were on the forefront of any conversation providing information. So that’s the first element of that, so medical information.

But-I completely agree with you that plain-language summaries definitely fill in this gap – this information, this literacy gap – when patients are looking for any information available.

KENNEALLY: And the impact isn’t just on patients and researchers, but on pharmaceutical companies like Ipsen. How is this going to change the culture, the approach, to your interactions with the public and with other researchers?

GORBENKO: We are part of the healthcare landscape, of course. And actually, it’s all of our collaborative efforts with academic institutions, with independent investigators and clinical sites. Of course, we have a mutual commitment here, and I think with a majority of our investigators, we agreed that we should be open. We should be transparent with patients and study participants.

Investigators try to do that through specific processes like – probably you’ve heard about new regulatory initiatives like lay-language summaries. Lay-language summaries are not about publication. It’s about a study research summary to be shared by investigators or independent sites. It’s a formal document, because plain-language summaries – it’s a publication. It’s a journal. But lay-language summaries, it’s just a regulatory commitment.

KENNEALLY: Finally, Dr. Gorbenko, I want to ask you about how this feels to you. Plain-language summaries may really mean a difference for patients. They may get better treatment, possibly live longer. How does it feel to be a part of that kind of process?

GORBENKO: It indeed is a big commitment, and it’s a big ambition for us. It’s all about health literacy, patient literacy, and a commitment to patient literacy. Definitely, I’m more than confident as a public health scientist also that health literacy is the basis of good health, good awareness, good understanding, and a healthy lifestyle – and prevention, of course. So it’s all these elements interrelated, but everything’s starting from health literacy. And plain-language summaries are definitely providing some access to science, access to scientific data, and definitely increasing the health literacy level of our patients, which is most important. That’s why I’m so excited to be part of that together with my colleagues from the global medical publications and communications team.



KENNEALLY:—Dr. Oleksandr Gorbenko, UK-based global patient-centricity director for Ipsen, thank you so much for joining me.

GORBENKO: Thank you very much. It's a pleasure to be in touch with you. Thank you.

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KENNEALLY: OpenPharma is a multi-sponsor collaborative project facilitated by Oxford PharmaGenesis, an independent, global consultancy providing communications services to the healthcare industry, professional societies and patient groups. In September 2021, OpenPharma contributors published recommendations that outline the minimum steps needed to develop discoverable, plain language summaries that are trustworthy, credible, and of high quality.

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KENNEALLY: Adeline Rosenberg is a medical writer in the patient engagement and Open Pharma teams at Oxford PharmaGenesis. She has written on plain-language summaries for the peer-reviewed journal *Current Medical Research and Opinion* as well as in the Scholarly Kitchen blog. Welcome to the program, Adeline.

ROSENBERG: Thanks so much for having me, Chris. It's great to be here.

KENNEALLY: I guess I would start by asking you to help us understand better how plain-language summaries, PLS, aims to make medical research and information not only understandable, but more accessible and inclusive.

ROSENBERG: Certainly. A big element of open science is really just about opening up science to everyone, not just the scientists and researchers themselves. And I think medical research, medical science, is a really key area that is particularly important, because it impacts policy, it impacts patients, it impacts everybody. So providing research in a readable format, in jargon-free text that everyone – or at least the broad public – can begin to understand and digest is a really great way to share your research with everyone out there.

KENNEALLY: What kind of audiences and which groups do you think will benefit from plain-language summaries?

ROSENBERG: Yeah. The short answer is everybody in medical research especially – and that includes patients, caregivers, patient advocates, and charities and organizations all that – but we're also talking about media and journalists, policymakers, anyone that has a need or a want to read and understand medical research.



KENNEALLY: Why is guidance necessary for plain-language best practice? Who are you trying to reach with this kind of guidance?

ROSENBERG: Yeah, at Open Pharma, we are a multi-sponsor collaboration, and we work to drive change in various different aspects of publishing of medical research. We work primarily with pharmaceutical companies and publishers, but we also work with others more broadly in our network, such as patient organizations and policy organizations and all sorts.

KENNEALLY: And you have emphasized that this is non-promotional, that what we're talking about here isn't marketing. It's publishing. That's an important difference.

ROSENBERG: It's a very distinct, important difference. A plain-language summary is not in any way an advertisement. It is simply the exact same content that is in the scientific publication written in a different way. If you wouldn't consider a scientific paper an advertisement, you wouldn't consider a plain-language summary an advertisement, because it will contain the same factual content without bias or promotion, hopefully.

KENNEALLY: And text-only summaries are probably the first and easiest way to go with plain-language summaries. They're more easily found in internet search engines and on PubMed. But there are other formats for plain-language summaries that are also acceptable and recommended.

ROSENBERG: You could do video abstracts, podcasts – there's so many different formats for different learning styles, which is really great. But certainly, as the first step, as a cost-effective and easy-to-produce step, text-based is a great start.

KENNEALLY: Well, certainly you are the immunologist, Adeline. I'm not. But I feel sometimes as if I almost need to be given all the information that comes at us from sources like the CDC in the US and the NHS in the UK. And it seems to me that whether we get past COVID-19 today, tomorrow, or next year, this is a situation that will be with us for some time to come. Science, science research, is really a part of our lives now.

ROSENBERG: Yes, definitely. I think that's one of the positives of the pandemic is that it's brought a lot of science to the forefront, and it's brought people into the conversations of science who might not have had that opportunity before.

KENNEALLY: Absolutely. And you've been a part of that, because in addition to being a medical writer, Adeline, you're also a rare disease patient advocate. So I want to ask you



how – as a member of a virtual community of patients, are you excited about seeing plain-language summaries become more common?

ROSENBERG: Completely excited. Even pre-pandemic, the online community has been a huge part of disabled and chronic illness life for many people who previous to lockdowns may not have been able to leave their homes because of their own health. So having access to Twitter and Instagram and other social medias has been really important. And a lot of what you see happening in those communities is the sharing of research. Here's something new that's happened in the field of the disease that I want to share about, and people discussing what might this mean? What could the impact of this be?

And especially within rare diseases, a lot of people, a lot of patients become experts in their own disease. They kind of have to be. But what'd be really great is for those that have not become the experts to have digestible information to share that research that they're already sharing, but not necessarily digesting or understanding. Yeah, just have research that can be given to everyone, I think would be really great.

KENNEALLY: Adeline Rosenberg, medical writer in the patient engagement and Open Pharma teams at Oxford PharmaGenesis, thanks so much for speaking with me today.

ROSENBERG: Thanks, Chris.

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KENNEALLY: The Future Science Group – which is self-described as a progressive, customer-centric publisher of medical, biotechnological and scientific research– moved in 2020 to advance plain language summaries to the journal article level. By publishing Plain Language Summary of Publication articles of clinical research as a standalone article, FSG expects patients will learn more about the options available to them and make informed decisions on their treatment.

Joanne Walker is head of publishing solutions at the Future Science Group, where she has spearheaded their plain-language summaries initiative.

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WALKER: We recognize that our readers are time-constrained, so they need as many tools as possible to really help them learn about content, help them keep up to date with new publications. So all of our articles that we publish can feature videos, podcasts, infographics, etc., just to really sort of bite-size content and make it really digestible.

Plain-language summaries is really a natural progression from this. They're written in easy-to-understand language, etc. We're recognizing that science is now being read –



COVID has really put science in the spotlight, and it's just being read by so many different audiences. That's why we really felt that we wanted digestible, easy-to-understand content that was just then accessible for everyone.

KENNEALLY: So what are the ways that you work with your FSG authors to help them make their research understandable for non-specialist audiences? This isn't something they've had to do before.

WALKER: In the first instance, we're encouraging all our authors to feature lay abstracts alongside their articles. These are short summaries of their work, should be written in easy-to-understand language, and they're published within the manuscript, and they can be read alongside the abstract. If any of our articles are behind a paywall, they can be read in front of the paywall. So they really are a really nice overview written to help anyone read about the content. And then it's sort of a teaser. If they understand the abstract, they might then want to go on to read the main article.

KENNEALLY: FSG is the first scientific publisher to publish plain-language summaries as standalone articles on their own. These are known as PLSPs, for plain-language summaries of publication. Describe the PLSPs for me.

WALKER: These are, yes, standalone articles published in any of our journals. There's numerous benefits of having them as standalone articles. I'll just sort of list them here.

Firstly, it means that they are assigned a DOI, so they're then independently discoverable. Although we are happy to publish supplementary plain-language summaries, having a standalone plain-language summary or PLSP really does make that article a lot more discoverable.

Because they're independently published in our journals, we also ensure that they are peer-reviewed. That then adds a bit more level of credibility to the article as well. They are also citable because they have a DOI as well. Also, they're really laid out – our in-house designers format these so they're a really user-, reader-friendly, infographic-style article. They're produced completely differently to our normal, traditional articles that we publish. There's lots of images, graphics, etc.

And then another main feature of these as well is that the PLSPs can summarize any article from any journal – for instance, articles from *NEJM* or *Lancet*, etc. – and we consider them to be acceptable secondary publications according to the ICMJE criteria. It means that these can be produced without breaching any sort of copyright or any of these publishing guidelines. And most other publishers that we are seeing that they are happy for us to publish these articles, because it helps everyone understand the article, and more often than



not, it's actually leading people to go on and read the original article. So it's helping them to get more readers on the original article that was being published in the article.

They're all published as open access as standard, because we just feel it's really important for everyone to be able to read these. Unfortunately with open access, you can't really see who's reading it, because it's just open for everyone. But what we're seeing on social media, etc. is a lot of patient organizations are sharing these articles, and it's great to see that they're being read by the people that we want them to be read by.

KENNEALLY: And it's important to emphasize that this is publishing. This is not marketing. These are peer-reviewed articles.

WALKER: Yes, all the PLSPs that we publish are summaries of articles that have already been published in another journal, whether it's one of our journals or from someone like Elsevier, Springer, etc. So we know that the article itself, in order for it to have been published, has already undergone quite a strict peer-review process. We know that the science is credible. The science is sound. We know that there's that level of credibility there.

But also the PLSPs themselves are peer-reviewed. They're peer-reviewed for scientific accuracy and how well they represent the original article, and then they're also peer-reviewed for how they read, how they're laid out, etc., as a plain-language summary. So we know that through that peer-review process, there's no cherry-picking of the data. If the article is sponsored by a pharmaceutical company, they're not misrepresenting the data, because it has to be a summary of the original article.

KENNEALLY: It seems to me that summarizing this kind of content for a lay audience is going to be an important skill for researchers and others in the scientific community moving forward.

WALKER: Yeah, you're absolutely right. It's just really hard for someone to explain something in easy-to-understand language when they're so familiar with the topic.

I think it really does depend on who you want to read your summary. If you want your article to be read by other scientists who may not be familiar with your field, but other scientists, then you'd possibly write the summary in a bit more of a technical way. That's absolutely fine. But if you do want your summary to be read by a lay audience, then you really do need to make it clear – have a colleague, have a non-researcher read it to make sure that they're aware – just have other people read it before you go on and submit it to a journal or something, because it really is important. You could ask your mum or dad to



read it, even. Because if they're non-scientists, they should be able to understand what's being said.

KENNEALLY: It's also increasingly common for patients to be authors of PLSPs. That's because I understand that Future Science Group believes that the patients themselves are experts. What do you mean by that?

WALKER: They know what the symptoms mean to them. They know what might be relevant. Patients as authors is such a really interesting topic. I know that it's quite a polar subject as well. Some journals don't like it. Other journals do. At FSG, we do like it, and we do encourage patients to be authors. They provide a really rich experience.

In terms of PLSPs, I think patient authors really help with the format of these. It could be that the PLSP is summarizing the safety and efficacy of a new treatment. And it could be that because of the way traditionally scientific articles are written, with your methods, your results, you looked at the efficacy, and then it goes on to study the safety – but it could be that that patient author thinks, well, actually, it's the safety that's the more important thing that I think about. Is the drug going to give me really horrible side effects? So they may help them with the structure of the article, and they may help think, well, actually, reverse it. Put the safety data first and then put the side effects data. It's really gaining experience from them in terms of how they think these articles should be written and structured as well.

KENNEALLY: As we've seen in the COVID-19 pandemic, there is a – I'll call it a credibility gap between scientists and the public. Do you think that plain-language summaries can help to close that gap?

WALKER: Everyone is interested in plain-language summaries. It's all a big buzzword. But the main thing is that readers or patients themselves still – we need to educate patients themselves that these types of articles exist. So they need to know that somewhere, you can Google plain language and X, Y, and Z, and you should then hopefully be able to find accessible information that they can read about a subject. And then once they've delved further into the subject, they can then maybe find the published article, the plain-language summary, that sort of thing. So I really think it is closing the knowledge gap between doctors and patients – lay readers.

KENNEALLY: And there are other benefits for the pharma-funded medical research field, right? This is a helpful step for those kinds of companies to begin to expand their engagement with patients.



WALKER: Pharmacy companies can give doctors these plain-language summaries to help them then communicate with their patients and say, look, I'm considering giving you this new treatment. This is based on this research if you're interested. Here's a plain-language summary discussing this research. So it is a really good way to help patients and doctors communicate with each other.

But also, these tools are good for doctors themselves as well. Rather than perhaps spending half an hour reading all the data in a scientific article, they can spend five, 10 minutes reading a summary, and then they'll think, oh, actually, I'm going to go on and read the full article when I have time. There's just benefits for everyone, really.

KENNEALLY: And in November, to mark Lung Cancer Awareness Month, FSG posted a group of plain-language summaries for articles on lung cancer that appeared in *Future Oncology*, one of your journals. I had a look at those, and I found it remarkable how much information was conveyed in such a small space. Even there was a pronunciation guide for the various drugs – very helpful indeed. So what's it like to be part of an effort that may mean more patients get better treatments and may live longer?

WALKER: And it's just great to see how well these are being read. We're looking at some of the data, the metrics of the readership – some of the articles that we published a few months ago now have got 2,000, 3,000 downloads, which – it's just really good to see that they're being well read and they've got good altmetric scores. They're being shared on social media. So it's just really great to see the impact these are having.

We've also received some really good feedback. With all articles that we publish, we send them to any relevant patient organizations, and we're getting feedback such as, oh, these are great tools. This is exactly what we've been looking for – that sort of thing. So it's really just nice to see that positive reinforcement of what we've been doing.

KENNEALLY: I'm sure it must be a really great feeling. And it's important, too, professionally, because you're part of seeing a change in something that for the last three centuries hasn't changed very much at all – the scientific article.

WALKER: Exactly. We recognize ourselves that the format of these plain-language summaries are still very much constrained within the format of what a scientific article should look like. And I was actually having a conversation with one of the patient experts that we work with, and he said, have you ever thought about sending this off to a graphic designer who doesn't work in publishing to see what they might do with it, just to completely turn the whole layout, turn everything on its head? We were a bit – ooh, that might be a bit too far. But it's definitely something that we'd like to consider – just really playing with the format of these and just making them so much more – ultimately, it's all about patients



being able to read these. So if it means that we have to come up with a different format or a different way that they're accessed, etc., I think we're all for that. We're just going to see how it all develops.

KENNEALLY: Joanne Walker, head of publishing solutions at the Future Science Group, thanks so much for speaking with me today.

WALKER: Thank you. Thanks.

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KENNEALLY: Plain Language Summaries help to move published research beyond the basic definition of Open Access – availability – toward a more ambitious goal of understandability.

Plain Language Summaries may also be the fundamental infrastructure for strengthening science in an age of information overload. The bridge from pharma labs to kitchen tables will be built not brick by brick, but word by word.

That's all for now. Our producer is Jeremy Brieske of Burst Marketing. I'm Christopher Kenneally.

Thanks for joining me on Velocity of Content from CCC.

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