Plain Language Summaries "Go Beyond Language"
Interview with Dr. Catherine Richards Golini

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KENNEALLY: Science publications are typically written by scientists and for scientists, yet the audience for science is far wider, especially any reporting on medical breakthroughs in treatments of serious diseases. While plain-language summaries of articles and abstracts are increasingly available, the story is more complicated than plain.

Welcome to CCC's podcast series. I'm Christopher Kenneally for Velocity of Content.

In June, ISO, the International Organization for Standardization, based in Geneva, issued principles and guidelines for plain language. Dr. Catherine Richards Golini, a healthcare publications editor at Karger Publishers, advises that creating effective plain-language summaries requires looking beyond the language. She says that editors and scientists should have an understanding of health literacy in the general population and an appreciation of patient preferences. Dr. Richards Golini joins me now from London. Welcome to the program, Dr. Richards Golini.

RICHARDS GOLINI: Thank you very much, Chris. And thank you for having me on the program.

KENNEALLY: The subject of plain-language summaries is an important one for everyone in science and outside of the profession. A graph of plain-language summaries available on PubMed Central shows them emerging just less than a decade ago. What are plain-language summaries, and what's it like to write them?

RICHARDS GOLINI: Well, let's define a plain-language summary first – PLS for short. I'll probably refer to it as a PLS in this program. It's a condensed version – sometimes as short as two sentences, and that's not advisable – a condensed version of complex scientific or technical or medical information, and the aim is to present it in a clear and understandable way so people outside of that discipline or industry can understand it.

They can look like a short paragraph. 200 words is quite typical, actually, in a journal – 200 or 250 words. But they are increasingly looking like infographics. Sometimes, they can be eight or 10 pages long. I've seen video PLS, animated, interactive. So pretty much anything goes, I think, at the moment with the format of a PLS.

The concept of plain language has been around a long time, as you know. I think it first kicked off in the States in the early '70s as a kind of kickback against the gobbledygook of government bureaucratic communication. This was swiftly followed by the legal profession, who said, yes, we've got to simplify this. Nobody can understand anything we're saying. And by the end of the '70s, the plain-language campaign in England began, and off it went.

The graph in PubMed is interesting, though, because what that shows us – it's a snapshot, but it's showing us how many PLS or papers with the word PLS in the title or plain-language summary in the title have appeared in journals. This is what we're seeing. More people are writing them. They're getting published.

It doesn't mean, though, that we can find them easily. There must be an awful lot of PLS that aren't appearing in the PubMed data, if you like. There's no central repository for them. That's something that's a real issue, something that we need to be working on to make it much more accessible for people to find them, much easier.

KENNEALLY: As a healthcare communicator, what's it like to work on writing, crafting a PLS?

RICHARDS GOLINI: Well, it all depends on the kind I'm working on, I think. I think the fairly straightforward, text only, 200 words – it's fairly straightforward to do. I've been working with language for the best part of 30 years. My doctorate studies were in clinical patient communication, so I have a heightened degree of sensitivity to appropriate language.

Where it gets more complex, I think, is when we're looking at producing eight or 10 pages of infographics, because then I'm working with an illustrator, the person who's doing the infographics.

KENNEALLY: Explain what you mean that plain-language summaries in healthcare go beyond language. What other considerations go into developing a compelling PLS?

RICHARDS GOLINI: Well, plain-language summaries, in common with healthcare materials in general, is about health literacy. The ultimate aim is to support health literacy. So we're not talking about literacy here. Literacy is about reading and writing. We're talking about health literacy, which is about many, many different things and is a multifactorial concept. You can actually have very good literacy and still have low health literacy, so they're not particularly related.

Health literacy is about our ability to understand healthcare information, to evaluate it. Is it reliable? Is it trustworthy? That's a big thing at the moment, of course. Health literacy

is about being able to communicate effectively with healthcare providers – asking the right questions, understanding the responses we get back, expressing concern or worry, this kind of thing, and to express our preferences. And I think health literacy is also about being able to act on the information that we're given or that we read or that we hear to make informed decisions about our healthcare and the healthcare of the people that we're responsible for – our loved ones, our children, etc.

I think the fact is that plain-language summaries and healthcare materials have one aim, and that is to improve the health literacy of the people reading them, so they can take a central role in their own healthcare. They can manage their own healthcare and the people around them. That's the plain-language version of what I've just said. (laughter)

KENNEALLY: An area where plain-language summaries can certainly impact healthcare is in the patient/healthcare provider relationship. What have you heard about each side's views of the effectiveness and the impact of PLSs?

RICHARDS GOLINI: There aren't as many studies as you might think when it comes to effectiveness, preferences, etc. But what we have got are some studies where patients show that they like plain-language summaries. Patients are already accessing research papers and journals and complex pieces of text. Some of them may be struggling to understand what they're reading. But the drive and the motivation to read is there. The drive for that information is there. I've seen a number of studies or a handful of studies where the figure quoted is about 50% of patients surveyed say yes, they're accessing research online, and yes, plain-language summaries are great, because it means I can now understand what I want to read.

I think with regard to healthcare professionals, it's again an interesting picture. I'm aware of a paper from about 2018 – so we are going back a bit now – where around 90 neurologists were surveyed about plain-language summaries, and about half of them said they found them useful. Half of them said – well, just under half – they were neutral. They had no opinion. They were indifferent to them. And around 8% said they were not useful at all. (laughter)

Well, things have changed, and I would be interested to see a similar study now, because I think there is evidence that HCPs who are positive about PLS are all saying the same thing. They're saying, yeah, this can speed up communication. This can help me communicate with my patients. And I can actually give this to my patient. I can print it off, and my patient can go away, even if they've never even heard of PLS. I can help my patient understand what it is that I've said to them face to face. It's a support.

KENNEALLY: A very interesting study published in May in *JAMA Internal Medicine* concluded that when responding to patient questions, AI-based chatbots gave answers that were more detailed and more empathetic than did physicians. Do you expect publishers will begin to use ChatGPT and generative AI chatbots to create these plain-language summaries, and do you welcome that development?

RICHARDS GOLINI: Yes and no. (laughter) I know that study that you're referring to, Chris, and I love it. I just love it. I think it tells us a couple of things – firstly, that artificial intelligence is way more capable than some of us would care to admit. It terrifies me and fascinates me in equal measure. It tells me that artificial intelligence has learned very quickly what empathy is and how to demonstrate empathy. And it tells me that we can use whatever it is that AI has learned to help these physicians who are still struggling to sound empathetic with their patients.

Chatbots are great. It works on a corpus of what you've given it. You tell it what it needs to look at, and that's all the data that you want it to look at. It doesn't go outside that. So great for answering those questions that perhaps your medical studio finds they're overwhelmed with, etc.

There are an awful lot of patients who are involved now in writing PLS, because they are great reviewers. They are the people that need to look at it and say this works, this doesn't work. In terms of basic simplifying language, yes, of course artificial intelligence can do that. Making it look great, reviewing it as a patient would – hopefully it can't do that yet, and I'll be retired before it can. (laughter)

KENNEALLY: Dr. Catherine Richards Golini, a healthcare publication editor with Karger Publishers, thank you very much for speaking with me today about the latest developments in plain-language summaries for healthcare information.

RICHARDS GOLINI: Thank you, Chris. It's been a pleasure.

KENNEALLY: That's all for now. Our producer is Jeremy Brieske of Burst Marketing. You can subscribe to the program wherever you go for podcasts, and please do follow us on Twitter and on Facebook. You can also find Velocity of Content on YouTube as part of the CCC channel. I'm Christopher Kenneally. Thanks for listening.

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