

WEBVTT

61

00:06:42.240 --> 00:06:46.880

Participant 20: So this is the final study in my Phd, oh, okay.

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00:06:47.070 --> 00:06:50.680

Karen Gainey: So I submit, I'm due to submit at the end of June.

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00:06:52.120 --> 00:06:59.140

Karen Gainey: So so yeah, just to give you sorry, just as a quick housekeeping reminder. I'm recording this

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00:06:59.140 --> 00:06:59.460

Participant 20: Yes.

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00:06:59.942 --> 00:07:05.737

Karen Gainey: Session. Just the audio will be saved. And Zoom will will

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00:07:06.580 --> 00:07:22.299

Karen Gainey: provide a transcript. And I say to everybody, most people aren't too busy. But if you'd like to have a look at the Transcript, you're very welcome. If you're if you want to check anything for context or

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00:07:22.680 --> 00:07:28.595

Karen Gainey: any other reason. Just let me know. Okay, no, no trouble with that at all.

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00:07:30.380 --> 00:07:57.329

Karen Gainey: so yeah. So I I started off with a everything's around plain language summaries. So looked at a did a scoping review, looking at the guidelines in health and medical journals, and then follow that up, looking at the guidelines, and compared those to actual plain language summaries to see how closely they compared quite varying results

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00:07:57.330 --> 00:07:58.050

Participant 20: Right.

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00:07:58.050 --> 00:08:18.325

Karen Gainey: Not many (publisher) journals, though. So and just about to be published. Is a series, I'll call it interviews much like this, but with people with chronic medical conditions. Asking who read plain language, summaries

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00:08:19.400 --> 00:08:33.409

Karen Gainey: and asking them what they why they read them, what they get out of them what they like, what they don't like, what works, what doesn't work. So put that together to try. And now ask

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00:08:33.809 --> 00:08:48.469

Karen Gainey: journal editors, people in publishing to kind of find out. Well, I know what's out there. I know what the audience likes which may or may not be realistic. So now I want to really find out

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00:08:48.760 --> 00:08:49.790

Karen Gainey: what

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00:08:50.812 --> 00:09:06.290

Karen Gainey: from your end is. Your thoughts and perspectives on things and what goes on, I guess, to your thought like what is behind some decisions that

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00:09:06.290 --> 00:09:06.610

Participant 20: Right.

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00:09:06.610 --> 00:09:18.650

Karen Gainey: Around publishing plain language summaries with (publisher) Plsps as well, and any other kind of media, like that visual

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00:09:18.770 --> 00:09:25.190

Karen Gainey: summaries, like infographics, audio podcasts, etc.

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00:09:25.800 --> 00:09:35.500

Karen Gainey: Any barriers and facilitators, all of that kind of thing. So wanting to kind of really close that loop, I guess

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00:09:35.500 --> 00:09:52.779

Participant 20: Yeah, yeah, I'm so excited to be able to help. And I'm just excited that you're doing this type of research. It's it's wonderful. And congratulations on being so close. I

mean, I said, full time, but being in school, I would not ever consider that anything other than just a full time

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00:09:52.950 --> 00:10:06.030

Participant 20: workload my sister got her Phd. And a friend of mine is doing hers, and I think every day I'm like, oh, I'm so glad I'm not trying to do this. I just, I admire the work ethic and the

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00:10:06.340 --> 00:10:08.056

Participant 20: what you're putting into it.

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00:10:08.590 --> 00:10:12.050

Karen Gainey: Oh, thank you. It'd be nice to have it done.

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00:10:12.050 --> 00:10:13.040

Karen Gainey: Yeah. But

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00:10:13.684 --> 00:10:28.069

Karen Gainey: yeah, I just love the area. And it's funny how my perspectives have changed from the time I began to now, which I guess is good. That's what it's meant to

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00:10:28.070 --> 00:10:28.550

Participant 20: Right.

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00:10:28.550 --> 00:10:28.880

Karen Gainey: Wow!

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00:10:28.880 --> 00:10:29.440

Participant 20: Right.

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00:10:29.440 --> 00:10:36.050

Karen Gainey: On this area, and particularly your actually the last person I'm talking to

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00:10:36.050 --> 00:10:36.890

Participant 20: Oh, okay.

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00:10:36.890 --> 00:10:46.211

Karen Gainey: I can bring everything together. Which is great because you're probably one of the most experienced people. I've read a bunch of your stuff.

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00:10:46.570 --> 00:10:49.150

Participant 20: Oh, I'm learning every

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00:10:49.150 --> 00:11:03.799

Participant 20: day. I always feel I was. Gonna say, I've seen your name and so much of the plain language summary stuff that I've done so. I feel like you're one of the ogs of plain language summaries. So yes.

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00:11:04.130 --> 00:11:05.270

Karen Gainey: No.

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00:11:05.580 --> 00:11:12.940

Participant 20: Yeah, I your name is associated with something I I don't know. I just remember being very impressed. So

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00:11:12.940 --> 00:11:14.060

Karen Gainey: Oh, thank you!

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00:11:14.060 --> 00:11:15.460

Participant 20: Yeah, yeah.

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00:11:16.030 --> 00:11:20.030

Karen Gainey: I see (name), and I'm like must read that, save

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00:11:20.460 --> 00:11:20.890

Participant 20: Breaking.

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00:11:21.997 --> 00:11:29.462

Karen Gainey: Because I'm i 1 of the things I've really learned talking to (name) and

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00:11:30.790 --> 00:11:34.280

Karen Gainey: oh, I forget the other person's the person from. But

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00:11:34.280 --> 00:11:35.640

Participant 20: (name).

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00:11:35.640 --> 00:11:36.760

Karen Gainey: (name)? Yeah.

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00:11:36.760 --> 00:11:37.500

Participant 20: Yeah. She's

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00:11:37.500 --> 00:11:43.010

Karen Gainey: (publisher)

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00:11:44.270 --> 00:11:50.410

Karen Gainey: (publisher). Yeah, yeah. Was that, were you part of that

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00:11:51.020 --> 00:12:08.200

Participant 20: I did not. I'm the one of the only 2 people that did not come from (publisher) and like our 30 team members. So we laugh really hard about that. And because it's even more people since (publisher) acquired (publisher) at the end of 2,000

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00:12:08.380 --> 00:12:10.209

Participant 20: or 2023.

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00:12:10.310 --> 00:12:31.610

Participant 20: I'm trying to date that back too far. So that's how (name's) on part of the team now, and I've learned speaking of learning so much. It's been such a treat working with her. She is so, and she's she's worked on them like hands on, for since the very beginning of plsp, so it's I'm learning so much from her.

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00:12:31.610 --> 00:12:41.390

Participant 20: It's wonderful to be with people. I always like being with people that know more than me, because I feel like, maybe I can get some of that from osmosis just being around it, and then just asking lots of questions

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00:12:41.700 --> 00:12:43.899

Karen Gainey: Yeah. And she's so enthusiastic

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00:12:43.900 --> 00:12:58.640

Participant 20: Yes, it's just nicest person. Everybody's amazingly, wonderfully nice in this industry. I think it's a real passion project for all of us. I haven't met one person that doesn't have a really personal commitment to the plain language summaries

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00:12:58.800 --> 00:13:02.400

Karen Gainey: Agreed. Yeah, in fact, that's

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00:13:04.070 --> 00:13:14.402

Karen Gainey: That's come through in so many of the interviews. That and that's 1 of the things I'm trying to understand. Sorry I just moved this table.

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00:13:15.060 --> 00:13:20.140

Karen Gainey: so I've just taken some medication. It has a bad taste.

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00:13:20.140 --> 00:13:26.889

Karen Gainey: Yes, to get rid of the taste is that

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00:13:27.170 --> 00:13:51.629

Karen Gainey: sometimes there are barriers and different levels of autonomy between the publisher and the journals depending on the relationship, whether there's a society involved different sorts of things. But what seems to drive change, or the implementation of plain language summaries is people, and their passion or desire for them.

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00:13:51.630 --> 00:13:58.070

Karen Gainey: Yes, and whether or not they they happen, or when they happen, is

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00:13:58.960 --> 00:14:08.249

Karen Gainey: not always under in their within their control. But it's that initiative seems to come through very

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00:14:08.250 --> 00:14:09.330

Participant 20: Yes.

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00:14:10.050 --> 00:14:10.860

Karen Gainey: Yeah.

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00:14:11.450 --> 00:14:22.649

Participant 20: How long have you been working on plain language summaries, because I always try to figure out like I came into it like at the end of 2,019, when they were just starting to really pick up some momentum

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00:14:24.040 --> 00:14:31.689

Karen Gainey: Yeah, I started my degree October 2018

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00:14:31.900 --> 00:14:35.569

Participant 20: Okay, been in it. You've seen that whole trip?

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00:14:35.570 --> 00:14:35.970

Participant 20: Turns out.

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00:14:35.970 --> 00:14:36.819

Participant 20: And yeah.

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00:14:36.820 --> 00:14:40.500

Karen Gainey: Yeah, yeah, it's oh, it's the timing's been amazing.

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00:14:40.500 --> 00:14:42.630

Participant 20: Oh, it's incredible!

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00:14:42.910 --> 00:14:49.029

Karen Gainey: Yeah. And then the pandemic. I think it's 1 of the few areas where

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00:14:49.910 --> 00:14:56.419

Karen Gainey: it's actually, in a way, kind of helped this area of misinformation, and and so

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00:14:56.420 --> 00:14:56.910

Participant 20: Yeah.

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00:14:56.910 --> 00:15:05.260

Karen Gainey: That's what got me doing. My Phd. I was bedridden for years in Facebook groups for Fibromyalgia and seeing so

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00:15:05.640 --> 00:15:06.910

Karen Gainey: Information yeah

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00:15:06.910 --> 00:15:07.530

Participant 20: Yes.

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00:15:07.530 --> 00:15:14.089

Karen Gainey: Decided. I've got to do something about it. Well, I was doing something about it, but not getting anywhere, so I thought, all right.

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00:15:14.090 --> 00:15:14.670

Participant 20: Brilliant.

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00:15:14.670 --> 00:15:17.129

Karen Gainey: Maybe if I do something more formally I might

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00:15:17.360 --> 00:15:40.390

Karen Gainey: get some traction. And that led to this, and I discovered language summaries looking for topics and fell in love with it. And just see so much, so much potential super excited to discover plsp which I've only just discovered this year or late last year.

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00:15:40.390 --> 00:15:40.710

Participant 20: Yeah.

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00:15:41.895 --> 00:15:48.299

Karen Gainey: They fit so many gaps that I've sort of seen and

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00:15:48.300 --> 00:15:49.040

Participant 20: Yes.

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00:15:49.040 --> 00:16:02.060

Karen Gainey: And they seem to really fit. So I'm super excited to see where that evolves, and love to hear your thoughts on, where obviously

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00:16:02.220 --> 00:16:11.300

Karen Gainey: I know you can probably only speak for (publisher), but please draw in any experience. You you like, if if it's

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00:16:12.148 --> 00:16:16.060

Karen Gainey: outside of (publisher) working with

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00:16:17.023 --> 00:16:23.330

Karen Gainey: these summaries elsewhere. Or not that that's that's totally

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00:16:23.500 --> 00:16:31.710

Karen Gainey: totally useful. But yeah, keen to see where you think that might evolve. As I understand, it's fairly new area

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00:16:31.710 --> 00:16:34.449

Participant 20: Alright. Do you want me to go ahead and talk about that? Now

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00:16:34.450 --> 00:16:35.829

Karen Gainey: You. Just yep. Go ahead

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00:16:35.830 --> 00:16:36.890

Participant 20: Okay. Alright!

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00:16:36.890 --> 00:16:45.829

Karen Gainey: And hopefully giving you a good idea of why I'm doing this and and what I'm hoping to to understand. So yeah.

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00:16:45.830 --> 00:16:46.370

Participant 20: Okay.

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00:16:46.610 --> 00:16:48.050

Karen Gainey: I'll just sit back and listen.

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00:16:48.210 --> 00:16:56.579

Participant 20: Okay, probably a lot at the very beginning is things that other people said. But I think what I love about plsp. I became.

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00:16:56.800 --> 00:17:18.338

Participant 20: (name) started them at (publisher) in 2020. And it's interesting to see the numbers because they like went from one to 20. I have to pull. I don't have them right at hand, but I can share those with you in an email afterwards. But, I just remember being at (professional association) annual meeting and hearing (name) talking about it, and (name) and

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00:17:18.660 --> 00:17:35.939

Participant 20: one of my colleagues here at work, Johnny, who is both my manager and (name's) manager, and I were like. We started the plain language summary initiative at (publisher) in 2019, and then launched plain language summaries, and I think 2020 or early 2021. It all blends together.

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00:17:36.259 --> 00:17:52.550

Participant 20: But then we saw that. And we're like we need to be doing this at (publisher), and I think, like you say it, they bridge the gap of, I think ultimately they're more discoverable because they have a doi, and I think so often the pls with the article

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00:17:52.930 --> 00:18:09.560

Participant 20: I think they're easier to see now, but when it comes to doing online searches it's very difficult to find those types of plain language summaries, whereas when you do a plsp, you have plain language summary in the title. If you search it on Google or pubmed, it's going to pull up.

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00:18:09.730 --> 00:18:18.829

Participant 20: and I think that combination of text and images I mean all the evidence that we have right now tells us that people prefer

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00:18:18.880 --> 00:18:42.630

Participant 20: infographics or some type of graphical pls or abstract to pretty much everything else. I think video abstract. So the other one that's up there. So it pulls those together, and I think it just. There's only so much you can do in a short text, pls in 250 words or so, or in a single infographic, whereas the Plsp. Allows you to expand. I think

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00:18:42.630 --> 00:18:59.939

Participant 20: my biggest concern sometimes is the length of them. I think they I've seen some of the (publisher) ones are now (publisher) ones that get up to be like 9, 1011 pages.

And I to me, that's a little overwhelming and very much. I think people with social media are incredibly focused on short

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00:18:59.950 --> 00:19:16.830

Participant 20: bits of information. I laugh because I do these videos on Instagram and my husband, he's on Tiktok. He's like you always make them too long. He's like it's got to be like 1015 seconds, because otherwise you lose people's attention. I think getting pls piece to that, 2 to 3, page

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00:19:17.270 --> 00:19:17.650

Karen Gainey: Thanks.

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00:19:17.650 --> 00:19:19.900

Participant 20: Sticking kind of that, as a

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00:19:20.160 --> 00:19:29.690

Participant 20: guideline would just help with people so that we don't lose their attention. And don't they don't miss out on any of the really important messaging that's in there.

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00:19:30.176 --> 00:19:45.559

Participant 20: I don't know if (name) or anybody else has mentioned it, but open. Pharma has put together a cross publisher group. And we're working on consensus, on plain language plsps. And I'm thrilled about that work because we're finally going to have.

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00:19:45.610 --> 00:19:58.080

Participant 20: It was interesting, because I think it had (publishers X & Y), and we all got in a room last October in London, because I was over visiting my team.

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00:19:58.080 --> 00:20:11.770

Participant 20: and we were pretty much on the same page with just everything which was exciting. So it was really straightforward to put the guidelines, and it stem from again. I'm probably repeating what other people said. We. I was in a meeting with

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00:20:11.770 --> 00:20:28.310

Participant 20: the pubmed and open pharma in February of 2024, and we were talking about like establishing an actual article type for plsps on pubmed versus just tagging it as pls. Or something, you know, just making them more discoverable, and they said, Well.

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00:20:28.550 --> 00:20:47.989

Participant 20: we could do it. But one of the main things we need right now is industry, agreement, and when I say, industry, like the entire publications community like the (professional association) community, but agreement on what they are. And we need some type of guidelines that are across publishers. So that was kind of the

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00:20:47.990 --> 00:21:03.850

Participant 20: reason that group was established by open Pharma, and I love that they're doing it because they did the PIs recommendations as well at the beginning, so it seems really a natural step to go from the PIs recommendations to now doing the Plsp guidelines.

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00:21:03.850 --> 00:21:19.509

Participant 20: and we have an abstract that'll be at the annual meeting in May and a poster about that initial work we've done, and the ultimate goal is to create like, not just a set of guidelines, but entire, like resource, Kit, for all the different things that you need.

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00:21:19.620 --> 00:21:44.168

Participant 20: like, one of the biggest things I think that'll be helpful is creating templates, so that when you ask for permission from authors and publishers, you know, having a template of how to ask for it, how to explain what a plsp is to those that are kind of plsp naive or plain language, summary, naive but just those little elements that make it easier for people to do pls or plsp, so

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00:21:44.630 --> 00:21:54.132

Karen Gainey: Coming back to circling back to what the future holds, I think. Just continue. I think we've made a huge step forward in that alignment now, and I think

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00:21:55.130 --> 00:21:58.229

Participant 20: Just seeing the momentum and how many.

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00:21:58.360 --> 00:22:21.799

Participant 20: how fast we're increasing just at (publisher) and publishing plsp. When you look at the (publisher) and (publisher). Figures where you had one in 2020, and we published 105 last year in 2024 in 4 years that type of growth. And then just seeing the numbers already this year we've published almost 30 in just the 1st 2 months of the year, and

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00:22:22.200 --> 00:22:38.500

Participant 20: I don't see that momentum stopping. I just think we're going to continue. It's going to continue expanding, and they have a lot of legitimacy already. But as more

publishers pick them up as they have guidelines in the industry. If we get them indexed on pubmed.

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00:22:38.500 --> 00:22:59.559

Participant 20: we're hoping to have this repository that this cross publisher group is also working on launched this year where we index pls and plsp's that's moving forward. We have like a framework. Now we have a sponsor, not a sponsor. But we're partnering with someone that is building it as we speak, which is so exciting after 2 years worth of work.

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00:22:59.570 --> 00:23:04.730

Participant 20: all of this is coming together to just continue that momentum forum

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00:23:05.200 --> 00:23:09.549

Participant 20: I think, coming. I think the length is one of the things I would really like to see

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00:23:10.080 --> 00:23:17.599

Participant 20: more consensus on, because that's the one thing that I get hung up on is having them be too long. But it seems to be outside the purpose of what

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00:23:17.810 --> 00:23:19.849

Participant 20: a plain language summary is

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00:23:20.230 --> 00:23:20.710

Karen Gainey: Yeah.

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00:23:20.710 --> 00:23:38.029

Participant 20: The other big issue is just some of these publishers that won't give permission for plsp's to be created from their content has really just been discouraging, and it's just a handful. But it's like New England Journal of Medicine. It's Jama, and it just completely.

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00:23:38.280 --> 00:23:40.239

Participant 20: They're coming at it from like a.

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00:23:40.500 --> 00:23:47.649

Participant 20: They're upset. They think that we're creating revenue off of their content. But it's very short sighted, because

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00:23:48.390 --> 00:24:06.550

Participant 20: that's not why any of us are in it. Yes, there's revenue associated with it. We have to pay to be able to publish them and all of that. But everybody who's in this is doing this for ultimately patients. And I think of those journals as also they're publishing, you know, incredible research. They want to make it.

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00:24:06.670 --> 00:24:20.149

Participant 20: We want to make sure it gets into the hands of patients that can understand it. And I'm a patient. I work in this industry. I have a hard time understanding a lot of the research out there. Yeah. So I know it's not.

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00:24:20.440 --> 00:24:41.769

Participant 20: It's just outside your experience level. Anyone who's coming across this information, we just want to make it. So it's clear. And if you said, it's about this misinformation disinformation online, we have to be doing something to combat it. We have to be putting out good information that people can understand, but I think

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00:24:41.900 --> 00:24:48.400

Participant 20: there's also efforts there to make it to clarify with those publishers what plsp are.

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00:24:48.550 --> 00:25:11.420

Participant 20: what they're not, and how much they benefit the original article and send people back to it like we already have evidence showing that people that read the Plsp. Then go back to that original article, and it's more likely to be cited. It's more likely it's going to have more views so that benefits everybody. It's a win-win situation for everyone. It's just communicating that to them.

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00:25:12.100 --> 00:25:18.530

Participant 20: Is there anything else in like the future that you would like me to touch on that I haven't thought of off the top of my head.

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00:25:18.790 --> 00:25:38.310

Karen Gainey: Yeah, there were a couple of things I wanted. That's that's an incredibly tight and concise summary. And I really appreciate that because you touched on some things others had discussed. But you really filled in a few gaps which was great. So I know. Adeline Rosenberg.

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00:25:38.310 --> 00:25:39.260

Karen Gainey: Yes.

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00:25:39.680 --> 00:25:53.169

Karen Gainey: and because I did. A scoping review on guidelines, came across some of her work and heard about the open pharma, and was following that with great interest, but didn't know it had expanded

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00:25:53.350 --> 00:26:05.139

Karen Gainey: so much, really, really excited for that. And yeah, (name) told me about the poster of presentation coming?

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00:26:05.140 --> 00:26:06.910

Karen Gainey: Yes, and said, city

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00:26:06.910 --> 00:26:27.210

Karen Gainey: a copy of that. So yeah, I'm really excited about that. And it's funny. It's so much of what's happening and what your team is doing. And with the the open Pharma group things that were kind of on my wish list in the very

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00:26:27.210 --> 00:26:29.430

Participant 20: Oh, that's great!

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00:26:29.430 --> 00:26:54.574

Karen Gainey: Yeah, like the the website. That with the searchable website, repository. That was one of the very early things I thought, well, maybe when I get to the end, if I need a job I'll try and create something like this. I don't know how I'll do that. So that's so exciting. So I think that's just such a was such a missed opportunity.

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00:26:54.950 --> 00:26:56.170

Participant 20: Yeah, yeah.

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00:26:56.170 --> 00:27:01.180

Karen Gainey: Thrilled to see some of these things happening.

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00:27:01.360 --> 00:27:02.830

Karen Gainey: Yeah, so

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00:27:03.480 --> 00:27:15.319

Participant 20: It's the same group of publishers when I say Cross publisher, this group of us that all publish Plsps, or, in (publisher)'s, the summary of research articles. And it's

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00:27:15.890 --> 00:27:28.189

Participant 20: there's 3 main initiatives we're working on that have kind of stemmed from that original repository idea that came about after the (professional association) annual meeting in 2023, and (name) kind of

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00:27:28.430 --> 00:27:38.353

Participant 20: let it in, saying that you know we need she, she and I think (name) and (name) from (publisher), had created this spreadsheet of

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00:27:39.510 --> 00:27:57.160

Participant 20: You know all the pls, pls and plsps, because, on the other hand, we also worked on. That is map evidence, database for digital features or publication extenders. So it all came out of that original work. We did. So then we had this cross publisher group. That's like, okay.

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00:27:57.160 --> 00:28:18.849

Participant 20: how do we go about creating a repository? And when you start it from scratch with a group of people that like building out websites is obviously not something that any of us do. But (publisher) had done that original work like, I think, the previous year to kind of look into doing something like that, and we were able to pick back up with that work as a cross publisher group.

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00:28:18.960 --> 00:28:19.645

Participant 20: And

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00:28:20.680 --> 00:28:34.750

Participant 20: you know, last year we started looking like, we said. What we don't want it to do is be connected to one publisher. We don't want to be. We want to be like a hosted with a nonprofit, so that it's publisher, not. It's not.

211

00:28:35.950 --> 00:28:56.760

Participant 20: There's no like one pharma company or med coms, or anybody like completely non-biased, solely run by someone that has no stake in publishing plsps, or could be accused of trying to create revenue. All this stuff. And we finally found that organization last fall. And it's just been exciting to see it move forward

212

00:28:56.760 --> 00:29:09.070

Participant 20: so that we hope to have that that very basic setup by the (professional association) Annual meeting because we put together a sponsor letter to go back out to the Pharma companies that were interested in helping launch it back

213

00:29:09.080 --> 00:29:13.179

Participant 20: a year ago, when we talked about doing it said, yes, we want to support this.

214

00:29:13.280 --> 00:29:23.759

Participant 20: So that's like the one main thing. And then what came from that is that Plsp project that the same group of people are involved in doing the guidance and the guidelines and the resources.

215

00:29:23.880 --> 00:29:36.419

Participant 20: And then the other pieces that we've worked with (professional association) to create a task force on the Plsp permissions issue for these publishers that are not giving permission. It's just goes to show that

216

00:29:36.650 --> 00:29:43.890

Participant 20: where we could be publishers that are competitive in that area. We're put that to the side. And

217

00:29:44.010 --> 00:29:47.430

Participant 20: we're we know that if we're doing what's right for

218

00:29:47.580 --> 00:30:03.091

Participant 20: the publication, the Plsp and the end user, the patient. That's what matters. And you know it benefits us all. But that's what the focus has been on. It's a passion project. And it's I came out of

219

00:30:03.530 --> 00:30:30.160

Participant 20: Another publishing industry that was very with what I was doing was very ad focus. It was all about revenue. It's very commercial, so it's completely awesome experience to join this group of people and the wider group of people that work on publication extenders and plain language summaries. Because I'm circling back to what we started with. It's just everybody is completely committed to it. We're doing this outside of, like our normal work hours.

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00:30:30.260 --> 00:30:31.230

Participant 20: we're.

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00:30:31.370 --> 00:30:45.370

Participant 20: you know, going above and beyond, and nobody questions it like we're just gonna keep going till it gets done. And that's how everybody is, including you, I mean. And Adeline, with her research, and because she's working on her Phd as well. And I just love

222

00:30:45.880 --> 00:30:51.599

Participant 20: guys are working on this research. Phds, that are plain language, summary and patient, focused

223

00:30:53.020 --> 00:31:14.770

Karen Gainey: Yeah, it's it's such an exciting time to be in this space. And when I started I had no idea it had grown so much I was kind of felt I was a lone sort of person, then gradually found some more people doing it, and, as you know, reached out to yourself and some others on LinkedIn and found my people.

224

00:31:14.770 --> 00:31:21.235

Karen Gainey: Yeah, very exciting. Can you help me understand how the

225

00:31:22.060 --> 00:31:34.830

Karen Gainey: how the I guess authorship? Not sure the right word. But when you're talking about New England journal, medicine drama, I guess the permissions work

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00:31:34.830 --> 00:31:35.590

Participant 20: Yes.

227

00:31:35.590 --> 00:31:37.730

Karen Gainey: With plsp, yeah.

228

00:31:38.540 --> 00:31:58.949

Participant 20: What originally well, and I would say, what we're still doing is Plsps are considered a secondary publication under lcmje criteria, and to meet that criteria to create a Plsp. It. We need permission from both the authors of the original article

229

00:31:59.100 --> 00:32:03.450

Participant 20: and the publisher or journal of the original article.

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00:32:03.610 --> 00:32:28.530

Participant 20: and we never have had an issue with the authors, and, in fact, for (publisher) and (publisher). We've always required that, like one of the original article, authors be also an author on the Plsp. Because I think one of the concerns of publishers not doing these that I've heard is that oh, you just start manufacturing plsp's off of all this research, and it's like, No, the Plsp. Is

231

00:32:28.710 --> 00:32:51.290

Participant 20: created from the original article with the authors agreement they author. They can be authors of the Plsp. As well. Most publishers require at least one author from the original article. So it's they're not going to give permission to do 10 plsp's off of one article that they've worked on, and there's and that like that was one of those concerns that's not happening.

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00:32:51.290 --> 00:33:02.600

Participant 20: The issue has been. And it just came up last year. We're getting the publisher permission to, you know. Approval. Permission is very vague wording with lcmje and it

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00:33:02.710 --> 00:33:14.579

Participant 20: we had not no one, I would say (publisher) had not encountered any pushback on that. But I think once (publisher) acquired (publisher), and there was like this fear that

234

00:33:15.430 --> 00:33:26.543

Participant 20: somehow well, obviously using plsp's as a revenue source. And these publishers started to talk to each other and decide. No, we're not gonna allow you to use

235

00:33:27.850 --> 00:33:43.429

Participant 20: to create a Plsp. From these articles. We're not going to give permission. In fact, we're going to send legal letters out to you, and, you know, threaten to sue you if you do that. It was really heavy handed and very discouraging, and also

236

00:33:45.110 --> 00:34:03.390

Participant 20: just between us, you know, these publishers are going out to other publishers. No, it's fine, it's not. It's most people know this. These publishers were encouraging other publishers to stop giving permission, like really active effort, to kill plsp's, which was discouraging and

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00:34:03.390 --> 00:34:03.940

Karen Gainey: Yeah.

238

00:34:04.130 --> 00:34:27.260

Participant 20: There's been. We did a lot of work with like copyright lawyers to better understand what could and could not be done. But at the end of the day. Even technically, if we're not, it's not a duplicate publication. It's allowable. Under Icmje. It is like there's technically there should be no reason that they're not allowed. But

239

00:34:27.659 --> 00:34:51.290

Participant 20: these publishers don't have to follow Icmje. They're just guidelines, they're not. There's nothing to say like, Oh, Icmj, you know this publisher said, We can. What are we going to do? They're like they said, you can't, that's all we can do. Not that they've ever. They've never given feedback, and we haven't asked. So it comes back around to. There's an educational opportunity

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00:34:52.630 --> 00:35:00.050

Participant 20: In some of the conversations I've had with publishers that aren't giving permission, and (name) has a lot more of these conversations, so I'm just

241

00:35:00.700 --> 00:35:22.639

Participant 20: my little bit of experience. She could expand on it if you need more info, but they don't understand what a plsp is. They think it pulls citations from the original article. But plsp's are not being cited like I said. They think that it could be used as a way to create a lot of revenue by creating bunches of plsp's from one article that's not happening.

242

00:35:22.640 --> 00:35:43.169

Participant 20: They think it's the same audience as like it's gonna pull audience away from the original article like, no, this is different audience. You know your audience is physicians or researchers. This is for a delay audience. So once we like, I sat down with 2 editors at (professional association) last year, and we had this conversation like, Oh.

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00:35:43.230 --> 00:35:47.930

Participant 20: this is really different than what we knew what we thought these were, and

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00:35:48.000 --> 00:35:50.910

Participant 20: it didn't change their stance. But I think

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00:35:51.700 --> 00:36:11.640

Participant 20: with the right type of conversation, and that's what we're hoping (professional association) will help facilitate is at the end of the day. The task force is working on putting together like an evidence story of why plsp's are important. The support they have from the industry and the task force is made up of Pharma medcoms, publishers

246

00:36:11.640 --> 00:36:12.180

Karen Gainey: We have.

247

00:36:12.180 --> 00:36:18.590

Participant 20: Patient representative now, so all the stakeholders to try to communicate and do it on

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00:36:20.290 --> 00:36:25.770

Participant 20: a very positive way of communicating, because we've never had a chance as a group. To sit down

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00:36:26.160 --> 00:36:31.039

Participant 20: will make a difference. I don't know, but all we can do is hope, and

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00:36:31.850 --> 00:36:35.600

Participant 20: we have to try. I think that's that's where we're at.

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00:36:35.600 --> 00:36:37.290

Karen Gainey: Yeah, yeah.

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00:36:37.290 --> 00:36:38.109

Participant 20: That hope.

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00:36:38.110 --> 00:36:47.150

Karen Gainey: Because it does. Yeah, because I guess it didn't occur to me till I think (name) mentioned it, or it might have been

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00:36:47.910 --> 00:36:49.500

Karen Gainey: might have been (name

256

00:36:52.830 --> 00:36:57.819

Participant 20: He's the lead on the task force for the Plc's permissions

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00:36:58.050 --> 00:37:04.720

Karen Gainey: Might have been him who mentioned it first.st I actually can't remember.

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00:37:05.200 --> 00:37:09.840

Karen Gainey: but it didn't occur to me that

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00:37:10.780 --> 00:37:14.656

Karen Gainey: the author couldn't just give permission. Right?

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00:37:15.320 --> 00:37:23.360

Karen Gainey: yeah, that there'd be this complication.

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00:37:23.740 --> 00:37:36.790

Karen Gainey: I mean, I've only published now 3 articles. But I thought the Creative Commons license meant that

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00:37:37.330 --> 00:37:43.589

Karen Gainey: that sort of thing would be within that framework

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00:37:43.960 --> 00:37:59.909

Participant 20: That's the tricky thing. Because Jama and like do not publish away under creative commons, they publish under a copyright transfer agreement. Oh, a creative Commons licenses where there's less of an issue. But that's not the journals that are being

264

00:37:59.910 --> 00:38:00.490

Karen Gainey: Difficult.

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00:38:00.750 --> 00:38:01.799

Participant 20: It's these journals.

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00:38:02.340 --> 00:38:07.829

Participant 20: It's an old, like a very old fashioned mindset, and their revenue is

267

00:38:08.390 --> 00:38:14.140

Participant 20: so they won't do open access. That's a huge issue right there.

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00:38:14.620 --> 00:38:15.550

Karen Gainey: Oh!

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00:38:15.550 --> 00:38:19.800

Participant 20: So anything moving toward? Yeah, it this. And that's where

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00:38:19.800 --> 00:38:20.470

Karen Gainey: Print.

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00:38:20.650 --> 00:38:21.130

Participant 20: Yeah.

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00:38:21.130 --> 00:38:22.359

Karen Gainey: Publication, model

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00:38:22.540 --> 00:38:24.060

Participant 20: Yes, and that

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00:38:24.060 --> 00:38:24.410

Karen Gainey: That's right.

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00:38:24.410 --> 00:38:37.995

Participant 20: It's so egregious is, it's it's just making research inaccessible to people. They can't access it. Sometimes they make it free to read, but then it gets ends up behind a paywall.

276

00:38:38.580 --> 00:39:01.832

Participant 20: it's it's just making it very like, oh, well, unless you're, you know, can pay thousands of dollars for access to our journal, or however, and or can pay the fee per article, which is nobody. Most people cannot afford to pay that over and over again. You can't read it, and we're also not gonna allow anybody else to summarize it so that you can understand it and access it.

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00:39:02.160 --> 00:39:02.510

Karen Gainey: Which is.

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00:39:02.510 --> 00:39:07.370

Participant 20: Completely against what most of us are doing this for

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00:39:08.270 --> 00:39:13.000

Karen Gainey: Right? So it's a whole different. It would require a whole different paradigm shift for them

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00:39:13.000 --> 00:39:13.670

Participant 20: Yes.

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00:39:14.140 --> 00:39:15.710

Karen Gainey: Yeah, as well.

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00:39:15.710 --> 00:39:20.790

Participant 20: I say they're in very. They're very committed to the subscription model, and

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00:39:20.790 --> 00:39:21.220

Karen Gainey: Yes.

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00:39:21.220 --> 00:39:36.739

Participant 20: That I've seen like when we flip journals from subscription to OA. It is you have to like leap off the cliff, and it takes a little while for the revenue to change. But that is the way it's going, and the longer

285

00:39:37.030 --> 00:39:47.729

Participant 20: this is just my own personal petition, the longer they wait the more trouble they're going to be in, because at some point everybody's gonna it's gonna be mandated away across medicine and health and

286

00:39:47.730 --> 00:39:48.300

Karen Gainey: Yeah.

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00:39:48.540 --> 00:39:51.770

Participant 20: They're just staving off the inevitable. And

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00:39:52.420 --> 00:40:16.309

Participant 20: I've said this so many times in presentations over the past 2 or 3 years since Covid. And you've made this point, too. Is that because publishers, it's not just publishing the research. Now we have to get it into the hands of the people that need it. And that's everybody. Everyone is our audience as soon as we have pubmed, and people can read research there and click on it. And most of it is, you know.

289

00:40:16.380 --> 00:40:35.389

Participant 20: at least the abstract can be read. We have a much bigger responsibility. We can't just publish it, and our job is done. We have to make sure that people can access it, and they can understand it otherwise. I don't think we're doing our jobs because we're not putting information out there. But we're not making sure that people

290

00:40:35.390 --> 00:40:49.190

Participant 20: understand what they're reading. And we're just then facilitating more misinformation and disinformation on social media and and elsewhere. And we can see where it's gotten us in the Us. Right now, in a really bad place

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00:40:49.700 --> 00:40:53.040

Karen Gainey: I feel for you. Yeah, yeah.

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00:40:53.040 --> 00:40:57.369

Participant 20: Does that? Is that know that enough for you? Yeah.

293

00:40:57.370 --> 00:41:03.890

Karen Gainey: I was missing that bit of understanding that makes total sense. Now.

294

00:41:05.270 --> 00:41:23.289

Karen Gainey: yeah. And and in fact, my supervisor said, for this current study, we should go for a high impact journal. I've looked at a few and saw they didn't publish anything like a plain language summary and thought, I'm going to just rule it out because I don't want to be hypocritical.

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00:41:23.290 --> 00:41:24.730

Participant 20: Right, right.

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00:41:24.730 --> 00:41:27.299

Karen Gainey: So I totally get

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00:41:27.800 --> 00:41:28.280

Participant 20: Yes.

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00:41:28.570 --> 00:41:36.559

Karen Gainey: Yeah, that makes a lot of sense. It's that entrenched publishing model. That's a barrier.

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00:41:37.225 --> 00:41:37.760

Karen Gainey: Yeah.

300

00:41:38.370 --> 00:41:39.600

Karen Gainey: So

301

00:41:41.930 --> 00:42:11.390

Karen Gainey: one thing I did ask (name) about was, and I I can't remember if it was it must have been about just the plain language summaries. Yes, it was just at (publisher) get back to that? But it was quite a specific question, and she said, This will be one for (name). If I could. Was I asked her why, if she knew where she didn't? Why, they're not mandatory.

302

00:42:11.980 --> 00:42:13.630

Karen Gainey: just wondering if you have any. Say

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00:42:13.630 --> 00:42:22.020

Participant 20: Yes, yes, I can. I feel comfortable speaking to this. We chose not to make them mandatory, because we would never

304

00:42:22.320 --> 00:42:29.440

Participant 20: want to discourage authors from publishing our research by making something mandatory at this point, that

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00:42:30.460 --> 00:42:31.910

Participant 20: how do I want to say it

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00:42:32.630 --> 00:42:48.480

Participant 20: in talking to? It's not so much on the. I think if it was just on the Pharma and medcom side. Making them mandatory would be no problem, because they're pretty much.

Everyone is including pls. At this point. Open Farm is looking toward making it like one of their.

307

00:42:48.770 --> 00:43:02.210

Participant 20: You know this is one of our not mandates, but one of our very highly recommended things that you publish open access and that you include a pls, it's more so on the academic side, and I think sometimes that gets lost.

308

00:43:02.300 --> 00:43:27.980

Participant 20: I lose sight of it, because the journals that are in my portfolio are much of it is almost all of it is sponsored research from Pharma, and we facilitate that like making it, you know, offering plain language, summary, and publication extenders. But on the academic side it is a real struggle for them to create plain language summaries and challenging to write them. And

309

00:43:29.470 --> 00:43:32.079

Participant 20: we don't want to shut down

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00:43:33.750 --> 00:43:44.882

Participant 20: like we want to still facilitate their research. And until something changes like, what? What's the model and lose, you know, but the model of the abstract, the

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00:43:45.280 --> 00:44:04.930

Participant 20: aims, the materials and methods. Right? Thank you. Until I think we had, like a set of guidelines to include a pls as part of that. That mandating. It just isn't appropriate, it should be, and I think the other thing too. Sorry. This is a little bit off top. My head is that

312

00:44:04.930 --> 00:44:05.890

Karen Gainey: Yeah, yeah.

313

00:44:05.890 --> 00:44:15.829

Participant 20: Plain language, some not every article suited for a plain language summary. And we really want to focus less like quality over quantity is making sure that

314

00:44:16.320 --> 00:44:35.569

Participant 20: people are choosing articles that are meaningful to patients like, put your energy into the type of research that you know patients are interested in. There's a lot of studies we publish, especially like the phase, one phase, 2, maybe, or even things that you know, some of these health economic studies that are.

315

00:44:35.770 --> 00:44:50.739

Participant 20: they can all benefit from a pls. But at the end of the day people have finite resources even on the Pharma side. So one of the workshop. I teach with (name) and a colleague, (name). We've done it a couple times for (professional association)

316

00:44:50.820 --> 00:45:06.339

Participant 20: for pls and patient engagement is figuring out a strategy of choosing which publications should have a pls, and then which publications you might develop a Plsp for and focusing on that research that is most important to communicate.

317

00:45:06.740 --> 00:45:21.960

Participant 20: And I. So that's and (publisher) has that pretty much across the board, like with our data sharing, we don't mandate that there's a that data be shared. We do mandate, that there's a statement like, even if it says There, you know

318

00:45:22.230 --> 00:45:38.200

Participant 20: whether it's a reasonable request or it's proprietary, and we can't share the data like we require a statement, but it doesn't. We don't mandate that the data has to be shared so that the pls and publication extenders kind of fall into that same mindset.

319

00:45:38.830 --> 00:45:40.549

Participant 20: Yeah, help yeah.

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00:45:40.550 --> 00:45:41.540

Participant 20: Light on it.

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00:45:41.830 --> 00:45:47.129

Karen Gainey: It does. That's what (name) thought, and that is what I thought

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00:45:47.130 --> 00:45:48.050

Participant 20: What's true.

323

00:45:48.330 --> 00:45:50.740

Participant 20: I've lost your I can't hear you

324

00:45:51.160 --> 00:45:52.270

Karen Gainey: How's that?

325

00:45:54.420 --> 00:45:56.409

Participant 20: How's that? Make sure it's not on my end.

326

00:45:57.220 --> 00:45:59.660

Karen Gainey: Yeah, I've just turned the volume up in case

327

00:46:04.210 --> 00:46:04.990

Participant 20: How's that?

328

00:46:04.990 --> 00:46:05.979

Participant 20: I can't hear you

329

00:46:06.300 --> 00:46:07.080

Karen Gainey: Weird.

330

00:46:07.390 --> 00:46:13.109

Karen Gainey: Okay, all right, I will.

331

00:46:14.320 --> 00:46:16.460

Participant 20: Do you want me to leave and come back

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00:46:19.970 --> 00:46:20.930

Karen Gainey: Okay.

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00:46:21.980 --> 00:46:22.370

Participant 20: Alright!

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00:46:22.370 --> 00:46:23.660

Karen Gainey: I'll do that too.

335

00:46:25.100 --> 00:46:26.310

Participant 20: I'll leave and come back

336

00:46:51.660 --> 00:46:52.919

Participant 20: Can I hear you now?

337

00:46:53.450 --> 00:46:54.460

Karen Gainey: How's that?

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00:46:54.460 --> 00:46:56.010

Participant 20: That's working. Sorry.

339

00:46:56.010 --> 00:46:57.819

Participant 20: Oh, great! I don't know, is it?

340

00:46:57.820 --> 00:46:59.300

Participant 20: There is on? But

341

00:46:59.420 --> 00:47:06.179

Karen Gainey: It might have been my end, because my wi-fi has been a bit patchy, so I'm glad that's good

342

00:47:06.840 --> 00:47:11.689

Participant 20: Good, and it sounds like you can capture everything. That full answer

343

00:47:11.920 --> 00:47:13.640

Karen Gainey: Oh, I heard you for sure.

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00:47:13.640 --> 00:47:14.310

Participant 20: Good, good.

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00:47:14.310 --> 00:47:23.750

Karen Gainey: Yeah, yeah. So I think if I'm understanding, this is what I've heard from a couple of other people is the concern is that it might.

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00:47:23.910 --> 00:47:38.150

Karen Gainey: One person very bluntly said, when they did have mandatory pls. This is for just a journal, not a publishing group. They were seeing a lot of incomplete submissions in the portal

347

00:47:38.370 --> 00:47:39.390

Participant 20: Right now

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00:47:39.500 --> 00:47:46.679

Karen Gainey: And then they change it to optional. That problem resolved

349

00:47:46.680 --> 00:47:47.120

Participant 20: Right.

350

00:47:47.925 --> 00:47:50.640

Karen Gainey: So is that kind of what you're

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00:47:51.050 --> 00:47:52.380

Karen Gainey: it does that kind of sum

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00:47:52.380 --> 00:47:55.510

Participant 20: I would agree with that. Yes, it's just a different.

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00:47:56.380 --> 00:48:05.510

Participant 20: It's hard to put into words. But when a group of authors does the pls, because they want to. It's a different quality of pls than when they're forced to.

354

00:48:05.740 --> 00:48:07.780

Participant 20: Okay.

355

00:48:07.780 --> 00:48:14.320

Participant 20: it shouldn't be something that they're like, you know, I'm being. I have to do this kind of thing. It's

356

00:48:14.920 --> 00:48:29.440

Participant 20: if it's written from like that good spirit like, we want to make this research understandable. And I think that's where, as publishers, we still have more work to do in educating, and as an industry, educating people. And I think

357

00:48:29.440 --> 00:48:45.510

Participant 20: one of the issues, too, is in Pharma. There's some pushback from some companies about the audience, for pls is, there's some that will say they are not, for patients like it can only go to the HCP. And it's on the Hcp. To communicate it. So again, there.

358

00:48:47.000 --> 00:48:48.890

Participant 20: you want to have people that

359

00:48:49.110 --> 00:48:56.059

Participant 20: agree on the pls, they're putting it in a journal where they feel the audience is right. That's going to get to that audience and not just

360

00:48:56.760 --> 00:48:58.680

Participant 20: each case is very.

361

00:48:58.820 --> 00:49:24.609

Participant 20: And I think that's the other piece is in publication plans. I think each manuscript is considered in itself like what is the right fit for this? What publication extenders should this have. It's not a 1. Size fits all solution like every paper, should not have a video abstract, a pls, a text pls, and then a Plsp, there's just not enough resources for that. So make the choice for each paper what is best for that?

362

00:49:24.915 --> 00:49:29.759

Participant 20: I think in the future it could change, and I think one of the reasons is because

363

00:49:29.830 --> 00:49:32.279

Participant 20: it's now like general agreement. I think

364

00:49:33.320 --> 00:49:42.380

Participant 20: I'm trying to think which policy was updated. It was Icmje with Gen. AI. Saying, like Gen. AI is now appropriate for a 1st draft of a pls.

365

00:49:42.580 --> 00:49:45.830

Participant 20: It came up in a meeting last week, and

366

00:49:46.190 --> 00:49:52.190

Participant 20: I think, publishers, we haven't. We are not offering like a Gen. AI. Platform or tool

367

00:49:52.190 --> 00:49:52.780

Karen Gainey: Soldier.

368

00:49:52.780 --> 00:49:54.690

Participant 20: Great Pos yet

369

00:49:54.690 --> 00:49:55.910

Karen Gainey: Yeah, yeah.

370

00:49:55.910 --> 00:50:08.180

Participant 20: Yeah, like, is that a tool that if we offered that like in the submission phase that they could generate a 1st draft and then fine, tune it from there. Would that help encourage?

371

00:50:08.460 --> 00:50:12.360

Participant 20: Think? There's a real opportunity to help that?

372

00:50:12.770 --> 00:50:29.960

Participant 20: Because anybody who's a writer we know it's getting it. It's getting it down like that 1st run through is the hardest part. Once you see something you can, then that's why I'm an editor instead of a writer, because I can take something and see like, okay, this, yes, this is what it needs to be. I can work with this. But having a blank

373

00:50:30.820 --> 00:50:39.990

Participant 20: page on a computer is a completely different story, especially for a plain language summary. And there's that's another area, I think, in the future is

374

00:50:40.720 --> 00:50:46.519

Participant 20: providing better guidance on what is appropriate. Plain language, because I think there's

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00:50:46.740 --> 00:50:55.378

Participant 20: we define it by grade level or school level or age level. But I still think it's very audience dependent.

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00:50:55.930 --> 00:51:02.749

Participant 20: and that there's no one. There's no consensus on what is currently the best. There's a lot of different

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00:51:03.110 --> 00:51:11.900

Participant 20: studies out there that are have similar findings about writing to a certain level, but that seems to be one of the most common

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00:51:12.060 --> 00:51:20.559

Participant 20: challenges that people talk about is what is plain language. When do I know like more? So when do I know that I've hit hit the mark with it?

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00:51:21.090 --> 00:51:23.540

Karen Gainey: Yes, what's that? Goldilocks spot right?

380

00:51:23.540 --> 00:51:40.930

Participant 20: Yes, yeah, the happy like. Yes, you know, the majority of people will read this and understand what it says, and that is a lot harder, especially for all of us that talk more technically. It's a lot harder to do than I've ever thought when I try to do it myself.

381

00:51:41.340 --> 00:52:00.940

Karen Gainey: Yeah. Well, I had to write one. I didn't have to write one for the journal I just published in but I did, because well, ethics required me to send a summary to all the participants, so I decided to do it as a pls. And it took me an hour and a half.

382

00:52:01.120 --> 00:52:12.389

Karen Gainey: and our Lab Sydney Health Literacy Lab has something called the Shell Editor, where you can put your text in, press a button, and it gives you a readout on readability, complex language.

383

00:52:12.650 --> 00:52:22.330

Karen Gainey: person-centered language, passive sentences, all of that which is really useful. So I fine-tuned it with that.

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00:52:22.440 --> 00:52:25.980

Karen Gainey: But yeah, I took a lot of

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00:52:26.870 --> 00:52:33.980

Karen Gainey: fine tuning and I had to decide what?

386

00:52:35.040 --> 00:52:40.649

Karen Gainey: Because one of the that was exactly what I was gonna ask you about next. Those 2 things

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00:52:40.650 --> 00:52:41.290

Participant 20: Right.

388

00:52:41.290 --> 00:52:47.579

Karen Gainey: Audience and generative. AI, because I think audience is one of the things

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00:52:47.920 --> 00:52:56.320

Karen Gainey: that's the most I think one of the most. I don't know whether it's the most important, most controversial.

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00:52:57.360 --> 00:53:00.169

Karen Gainey: almost misunderstood, or all of the above

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00:53:01.070 --> 00:53:05.737

Participant 20: I think it's a little bit of all. Do you want me? I'll stop there. I don't want to interrupt you

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00:53:05.960 --> 00:53:10.309

Karen Gainey: No, no, I guess just to put in context

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00:53:12.160 --> 00:53:14.760

Karen Gainey: to help frame. Maybe your answer

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00:53:14.760 --> 00:53:15.300

Participant 20: Yeah.

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00:53:15.300 --> 00:53:26.630

Karen Gainey: When I did my last study interviewing people who read plain language summaries of the 19 people I spoke to 18 had a minimum bachelor degree

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00:53:27.000 --> 00:53:34.240

Karen Gainey: 3 had postgraduate, and that was really surprising. So it kind of.

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00:53:34.240 --> 00:53:59.449

Karen Gainey: although not now that I've done more research and spoken to more people. So it's kind of I'm trying to understand. I ask everyone who you feel that your summaries are aimed at. So maybe the plain language summaries at the Plsps, whether that's different or it depends on the topic.

398

00:54:00.130 --> 00:54:01.450

Karen Gainey: And

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00:54:01.660 --> 00:54:12.230

Karen Gainey: is it? I guess what I've sort of you tried to use the term something like an informed consumer or the informed patient. So they're more health literate

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00:54:12.230 --> 00:54:13.220

Participant 20: Yes.

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00:54:13.220 --> 00:54:18.219

Karen Gainey: Rather than where I used to come from, which was the general public.

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00:54:18.520 --> 00:54:21.350

Karen Gainey: They're not the ones plain language summaries

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00:54:21.350 --> 00:54:22.070

Participant 20: Right.

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00:54:22.220 --> 00:54:24.019

Karen Gainey: It's a particular cohort

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00:54:24.490 --> 00:54:33.479

Participant 20: Yes, you hit the nail on the head. I don't. There's not too much for me to add to that other than saying, there's that happy spot where you're. I think

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00:54:33.710 --> 00:54:55.009

Participant 20: when we talk about pls or plsps, it's like thinking about your audience, because you want to make sure that one. If you're publishing like, more specifically, Plsp is

putting it in a journal that's going to hopefully reach that audience. And then we look at how we can at (publisher) How we can assist that through some social media work as well. But you're very right. You're not.

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00:54:55.150 --> 00:55:05.819

Participant 20: I think, what we've come out of this. And this isn't really addressed in the guidance or guidelines that the Cross publisher group has worked on. And maybe it's something we need to look into, is it.

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00:55:05.930 --> 00:55:16.670

Participant 20: The pls and plsp are not being written, like you say, for a lay audience, they very well may come across it in reading if it's available on a repository on pubmed

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00:55:16.670 --> 00:55:17.740

Karen Gainey: But

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00:55:17.740 --> 00:55:19.949

Participant 20: The target audience is

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00:55:20.290 --> 00:55:40.050

Participant 20: patients that are almost always more informed on the topic or more experts a lot of times than anyone else's, even their own doctors. And then healthcare professionals who have a more understanding of some of the technical language. So while you don't, you don't want a lot of jargon in there. You don't want to be overly technical.

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00:55:40.570 --> 00:55:42.099

Participant 20: You don't have to

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00:55:42.390 --> 00:55:50.700

Participant 20: create it for an audience that has no exposure to medical terminology or no exposure to certain diseases, and

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00:55:51.410 --> 00:55:57.533

Participant 20: you don't want to how to say you don't want to insult your audience that your target audience is for

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00:55:57.840 --> 00:55:58.460

Karen Gainey: Yes.

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00:55:58.460 --> 00:56:09.550

Participant 20: But it's something that we keep in mind with our peer review because we do have patient peer review. But we also bring in unlike plain language experts at times, because you do get patients that

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00:56:09.750 --> 00:56:18.799

Participant 20: I'm sure you are. I am incredibly knowledgeable about their disease and their therapy, and sometimes you do need a separate perspective of

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00:56:18.800 --> 00:56:19.350

Karen Gainey: Yep.

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00:56:19.790 --> 00:56:29.490

Participant 20: Saying, maybe this needs to be even less complexly written because we're everyone reviewing. It has such a strong scientific background

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00:56:29.490 --> 00:56:30.160

Karen Gainey: Right.

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00:56:30.360 --> 00:56:37.136

Participant 20: And again, I think that's where we don't have a lot of consensus on what finding that happy spot

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00:56:38.410 --> 00:56:43.430

Karen Gainey: That's yes. You've touched on kind of that Venn diagram kind of

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00:56:43.430 --> 00:56:44.090

Participant 20: Yes.

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00:56:44.090 --> 00:56:51.879

Karen Gainey: Way. And how big is that overlap of that person? Who knows? Because when I spoke to people

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00:56:52.420 --> 00:56:58.660

Karen Gainey: deliberately with chronic medical conditions, because the research shows they're high users of health information. And in

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00:56:58.660 --> 00:56:59.400

Participant 20: The top right

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00:56:59.400 --> 00:57:11.920

Karen Gainey: Is journal articles, but what we don't know is what part of the journal article they read. I still came out really none the wiser, except I know they read plain language summaries.

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00:57:11.920 --> 00:57:33.139

Karen Gainey: but often they use the plain language summary to help inform whether they want to read the rest of the article, and often using it in to help inform their current medical condition. See whether there's a new treatment or therapy they can then discuss with their treating practitioner.

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00:57:33.200 --> 00:57:40.359

Karen Gainey: or just to keep themselves informed and up to date. And I do that myself.

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00:57:41.370 --> 00:57:46.360

Karen Gainey: And so I'm in that category.

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00:57:47.200 --> 00:57:48.305

Karen Gainey: But

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00:57:49.630 --> 00:58:02.059

Karen Gainey: One of the things they did say they touched on they don't want. They don't mind a bit of jargon, because to avoid it altogether and dumb things down is patronizing exactly

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00:58:02.060 --> 00:58:04.050

Participant 20: That insulting a little bit. Yeah.

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00:58:04.050 --> 00:58:11.200

Karen Gainey: Salting. They use those words because they want a bit of meat, a bit of detail, because otherwise they can't. Really

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00:58:11.930 --> 00:58:13.820

Karen Gainey: it's not useful

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00:58:14.020 --> 00:58:14.600

Participant 20: Right.

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00:58:16.100 --> 00:58:17.619

Karen Gainey: Do you need to to go

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00:58:17.970 --> 00:58:24.200

Participant 20: I have another meeting, but it's not. It's 1 that I can go to late. So I'm just gonna send them a message because I

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00:58:24.860 --> 00:58:27.949

Karen Gainey: I want to continue talking. I don't want to brush off.

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00:58:27.950 --> 00:58:28.370

Karen Gainey: Tell me

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00:58:28.370 --> 00:58:30.270

Participant 20: Let me just send them a quick message

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00:58:31.021 --> 00:58:34.199

Participant 20: Cause. I want to talk about Gen. AI just a little bit. If you want

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00:58:34.200 --> 00:58:34.550

Karen Gainey: Yes.

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00:58:34.550 --> 00:58:37.809

Participant 20: Too, because I love. That's my favorite topic

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00:58:37.810 --> 00:58:42.510

Karen Gainey: Yeah, that'd be perfect. We can wrap up so.

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00:58:42.610 --> 00:59:08.940

Karen Gainey: But they did say, but I guess the point I was saying is, they they said that medical jargon, when related to their own medical condition, was something they

understood, and so they didn't think of it as medical jargon. So then they were saying, somebody newly diagnosed. May wouldn't have that same level of intimacy with the topic as someone who'd had it for

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00:59:09.120 --> 00:59:16.590

Karen Gainey: some time. So then it becomes very nuanced, and how

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00:59:17.470 --> 00:59:20.429

Participant 20: Where do you draw the line right

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00:59:20.570 --> 00:59:25.379

Karen Gainey: And so I'm trying to pick people's brains to see

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00:59:25.640 --> 00:59:36.650

Karen Gainey: is in your guidelines and editorial decisions. Have you come to any conclusions, or answered that

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00:59:37.320 --> 00:59:41.549

Participant 20: No, and I think I think that's 1 of the

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00:59:41.870 --> 01:00:04.090

Participant 20: things that you can. Probably highlight is something to take forward is finding it was even something that (name) that works with (name) and (name) and I. He's from (publisher). Joined (publisher) He's like we really need to address plain language like what is plain language. There's a lot of resources out there. But again, I think I mentioned earlier, they're not

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01:00:04.200 --> 01:00:05.800

Participant 20: providing consistent

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01:00:05.930 --> 01:00:26.670

Participant 20: guidance. And then there's like there's plain language. And then there's medical plain language, which is a little bit different. I think one thing I'm trying to think, who mentioned this to me recently, because this wasn't my thought. But with the Gen. AI is whether I think it will absolutely be possible in the future is to be able to like filter a pls through like

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01:00:27.350 --> 01:00:32.309

Participant 20: like very bait. Like to a great like, very for a lay audience.

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01:00:32.510 --> 01:00:55.110

Participant 20: for you know, or maybe have it be at what we're talking about, the patient, healthcare, professional level. But be able to adjust the language just like you would with a translation to if it needs to be like more simply like, is that something that you can run it through? Gen. AI like a specific tool and have it change that readability. So

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01:00:55.110 --> 01:00:55.730

Participant 20: hmm.

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01:00:55.730 --> 01:01:03.669

Participant 20: I mean, I always underestimate Gen. AI, because I just like it blows my brain at what it can do. But I think that would be well within its means.

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01:01:03.970 --> 01:01:04.300

Karen Gainey: In the future.

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01:01:04.300 --> 01:01:07.499

Participant 20: Future to be able to provide that for any

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01:01:08.080 --> 01:01:18.650

Participant 20: bit of text. I think you could put a plain language summary in there now, and say, can you explain this to me in more simple terms, and it would return something. The problem is

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01:01:19.230 --> 01:01:33.360

Participant 20: again, it's health information, and there's no way to. It's not peer reviewed once it's done like that. So there's always that concern like, is it? Appropriately translating it? And that's the hump we have to get over. And I think that's

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01:01:33.560 --> 01:01:47.009

Participant 20: that's the key thing about publishing, especially plsp, is that they are peer reviewed. And for our process we have a patient involved in peer review of every Plsp, we have scientific.

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01:01:47.010 --> 01:01:52.179

Participant 20: Yeah, yeah, know, peer Reviewer, we've added that as part of the process.

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01:01:52.300 --> 01:02:05.079

Participant 20: (publisher) just had a patient review, and we're like, well, no, let's add a scientific reviewer as well. And you know, if we need to, we have a plain language expert. We can pull on board. And that way we're getting those different perspectives

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01:02:05.350 --> 01:02:05.820

Karen Gainey: Hmm.

467

01:02:05.820 --> 01:02:08.260

Participant 20: I think that at this point is one of the

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01:02:08.420 --> 01:02:13.669

Participant 20: best ways we can counter that language issue, that we have

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01:02:14.170 --> 01:02:20.520

Participant 20: a minimum of 3 people looking at this in peer review with different perspectives that they can help us

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01:02:21.140 --> 01:02:28.730

Participant 20: get it to that point where it's written for the appropriate audience? Does? Am I making? Explaining that clearly

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01:02:28.870 --> 01:02:37.830

Karen Gainey: Yes, and then it just comes back to at the start, knowing what that audience is which might be different for every Plsp

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01:02:38.130 --> 01:02:38.790

Participant 20: Right.

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01:02:39.010 --> 01:02:42.729

Karen Gainey: But you have a starting point, and then you work from that

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01:02:42.900 --> 01:02:44.020

Participant 20: Exactly.

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01:02:44.180 --> 01:02:44.600

Karen Gainey: Yes.

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01:02:44.600 --> 01:02:52.899

Participant 20: When we this workshop, we've run about writing pls, that's 1 of those initial questions, who is your target audience?

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01:02:52.900 --> 01:02:53.720

Karen Gainey: Right.

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01:02:54.080 --> 01:02:54.940

Participant 20: And it's.

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01:02:56.070 --> 01:03:18.149

Participant 20: I think sometimes people forget to do that because they just think a plain language. Summary is a plain language summary, and they forget there's a lot of nuance within the plain language summary, and that's where I've seen that recognized more so in the last 2 years than initially. When the Pls conversation really took off in like 2,01820, 19

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01:03:18.880 --> 01:03:23.420

Karen Gainey: Yes, building in. What I see is they're very inflexible.

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01:03:23.710 --> 01:03:24.190

Participant 20: Yes.

482

01:03:24.190 --> 01:03:32.100

Karen Gainey: And if they don't, if they're not written to grade 8 level, they're seen as failed, failed, or

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01:03:32.100 --> 01:03:32.500

Participant 20: 8,

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01:03:32.500 --> 01:03:36.050

Karen Gainey: No good, and that's probably way too low, anyway

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01:03:36.660 --> 01:03:50.519

Karen Gainey: inappropriate. So the standards are maybe not realistic, and there's no flexibility to say, hey, 10 grade. 10 to 12 somewhere in there is fine.

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01:03:50.520 --> 01:03:55.160

Karen Gainey: but his just comes down to one word, and how often it's repeated

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01:03:55.410 --> 01:04:01.252

Participant 20: Exactly. And and that's another thing Adeline brings in this workshop that we've done.

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01:04:02.440 --> 01:04:04.890

Participant 20: is that when you're looking at.

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01:04:05.410 --> 01:04:08.344

Participant 20: I just lost my train of thought. It's not

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01:04:09.060 --> 01:04:13.180

Participant 20: Oh, just give me a minute. My brain just totally backfired on me.

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01:04:13.770 --> 01:04:14.899

Participant 20: It'll come back.

492

01:04:16.470 --> 01:04:24.189

Participant 20: Oh, the readability scores like not going off readability, scoring like saying a certain score is like a yes or no.

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01:04:24.480 --> 01:04:24.960

Karen Gainey: Yeah.

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01:04:24.960 --> 01:04:32.259

Participant 20: It's helps you in the development of pls. But ultimately your best way to know if it's

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01:04:32.750 --> 01:04:50.329

Participant 20: written for your target audience is to have your target audience read it before you submit it to a journal, and that's 1 of the big recommendations that comes out of that

for the development and writing. Part of it is having people that are your audience. Read it before you submit it.

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01:04:50.650 --> 01:04:58.939

Participant 20: and not depend on tools online to tell you if it's written appropriately. Nobody knows better than the person that it's destined for

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01:05:01.320 --> 01:05:03.379

Karen Gainey: That's a quote right there.

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01:05:03.890 --> 01:05:04.390

Participant 20: Good.

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01:05:05.110 --> 01:05:07.489

Karen Gainey: That's brilliant. I'm gonna timestamp that

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01:05:08.190 --> 01:05:18.550

Karen Gainey: fantastic. Yeah, all right. I know you've only got a few minutes. Yeah. Tell me your thoughts on generative AI

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01:05:19.520 --> 01:05:20.310

Participant 20: Oh.

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01:05:20.760 --> 01:05:27.699

Participant 20: I'll keep it. I'm going to start out saying that I'm not an expert in any way. I just find it fascinating, and I feel that

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01:05:27.820 --> 01:05:43.200

Participant 20: it is our future. It's not going away, so I need to embrace it and try to understand it as best I can. And one of those ways of doing that is, I started an AI Advancement committee like within our specific editorial group

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01:05:43.240 --> 01:05:58.089

Participant 20: to pull people in, and we meet once a month, and we talk about, how can we apply it to everyday use in our work? How should we be offering it as a publisher? How do we support our authors and our sponsors with generative AI.

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01:05:58.200 --> 01:05:59.140

Participant 20: And

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01:05:59.270 --> 01:06:27.189

Participant 20: it's really interesting because it there's so many things that you haven't thought of it. It can be a little bit overwhelming. But I'll stick to pls on this. I think there's been so much research already done with the posters at (conference) about using Gen. AI for developing pls. And it seems like the consistent message is, Gen. AI does a better job developing pls. And it's now

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01:06:27.500 --> 01:06:38.030

Participant 20: considered acceptable for that 1st draft. I think the challenge is, keep keeping our policies up with that. Because, for example, our (publisher) Policy, we

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01:06:38.180 --> 01:06:51.019

Participant 20: really hadn't addressed that at all. And when you look at it, you'd say, I don't know. Is it allowed to write? The 1st draft is that, you know, is that in accepted use, or is that not an accepted use. So I think

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01:06:51.490 --> 01:06:56.800

Participant 20: that having that, I think it's lcmje right that just recently changed their policy

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01:06:58.370 --> 01:07:01.329

Participant 20: on saying that AI could be used to develop a

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01:07:01.330 --> 01:07:02.050

Karen Gainey: I understand.

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01:07:02.050 --> 01:07:04.000

Participant 20: I'll have to follow up on that

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01:07:04.000 --> 01:07:05.480

Karen Gainey: Saved it. Yeah.

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01:07:05.480 --> 01:07:06.689

Participant 20: Okay. Good. Good.

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01:07:06.690 --> 01:07:07.470

Karen Gainey: Yeah.

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01:07:07.470 --> 01:07:15.349

Participant 20: And I think that is the most positive thing I've seen since. Gen. AI. Really kind of popped, was it? 2 years ago?

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01:07:15.510 --> 01:07:16.710

Participant 20: It's

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01:07:17.300 --> 01:07:28.960

Participant 20: where in the process is it appropriate to use it? And I think that puts it in a place where it's an appropriate use. It doesn't introduce too many issues, because

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01:07:29.160 --> 01:07:33.440

Participant 20: you're going to have the authors taking it from there. But

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01:07:34.030 --> 01:07:40.730

Participant 20: I won't repeat myself circling back to that conversation about just giving people a starting point. I think, yeah.

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01:07:40.730 --> 01:07:44.160

Participant 20: 1st draft use of Gen. AI could really help

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01:07:44.670 --> 01:07:52.289

Participant 20: us increase the amount of plain language summaries being created, and that as we facilitate that and make it easier for people.

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01:07:52.590 --> 01:08:02.220

Participant 20: We can move closer to making it more of a mandated part of a research manuscript because we're making it easier to do. It's not

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01:08:02.330 --> 01:08:06.820

Participant 20: seen as like a barrier to submission of your manuscript

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01:08:06.820 --> 01:08:08.580

Karen Gainey: Yeah. Gotcha.

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01:08:09.060 --> 01:08:18.789

Participant 20: And the I think the other thing I'll highlight on Gen. AI is just our biggest challenge is getting authors to appropriate appropriately disclose it, and it's not

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01:08:18.790 --> 01:08:21.920

Participant 20: on the fair various in any way. They just

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01:08:23.270 --> 01:08:30.849

Participant 20: like. We'll plug a manuscript into an AI platform and not realize all the implications that has for copyright. And

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01:08:31.279 --> 01:08:37.729

Participant 20: it, you know, losing confidentiality, losing data. We have had peer reviewers

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01:08:37.919 --> 01:09:06.699

Participant 20: do that. And so we're not. We're we. When we think it's happened. We're like, we just say, Ha! You know, how did did you use AI like, just have this conversation and try to educate people? Yeah. And that's more of a generic like that applies to everything that's being written and submitted for research publications. But I think especially because pls are seen as something that can. You know, Gen. AI can really be used for pls that we need to make sure we're

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01:09:06.839 --> 01:09:15.589

Participant 20: incorporating education around how to use it and making sure that people are disclosing, and what type of and how to disclose that use? And

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01:09:15.899 --> 01:09:25.219

Participant 20: publishers are. Now, we're now like adding questions to our submission systems like, did you use a generative AI, and like giving examples of what that means.

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01:09:25.470 --> 01:09:25.800

Karen Gainey: People.

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01:09:25.800 --> 01:09:31.769

Participant 20: Like in developing something, so that would apply to a Plsp submission. We we asked that upfront.

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01:09:32.130 --> 01:09:44.479

Participant 20: And we're looking at like how we're including that in our peer reviewer, like acceptance emails like when they accept an invite, we're saying, Make sure you do not put any piece or part of this manuscript.

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01:09:44.729 --> 01:09:52.620

Participant 20: including like a Pls or Plc into a AI platform like, don't use an AI platform at all.

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01:09:52.740 --> 01:09:55.290

Participant 20: Just do peer review as you used to

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01:09:55.700 --> 01:09:56.430

Karen Gainey: Yeah.

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01:09:56.740 --> 01:09:58.840

Participant 20: And that's it seems so

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01:09:59.320 --> 01:10:04.449

Participant 20: straightforward when you're used to when we're working in our world. I just think people

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01:10:04.730 --> 01:10:08.269

Participant 20: that don't understand all the ethics, implications

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01:10:08.430 --> 01:10:09.110

Karen Gainey: Yeah.

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01:10:09.110 --> 01:10:11.989

Participant 20: Use it without thinking about that at all. So

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01:10:12.100 --> 01:10:14.600

Karen Gainey: Yeah, that help provide some. AI,

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01:10:14.600 --> 01:10:19.629

Karen Gainey: that's that's awesome. I just had one really quick, quick question

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01:10:56.820 --> 01:11:06.480

Karen Gainey: I'm wondering is the term plain language summary of publication a copyright term? Or is that a copyright process

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01:11:07.980 --> 01:11:09.120

Participant 20: No.

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01:11:09.500 --> 01:11:09.880

Karen Gainey: It's

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01:11:09.880 --> 01:11:11.440

Participant 20: Say accepted

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01:11:11.860 --> 01:11:19.949

Participant 20: term, and this is something we hashed out with the cross posture group, with the open pharma consensus on the guidelines is what to call them.

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01:11:20.110 --> 01:11:21.959

Participant 20: and the agreement was

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01:11:23.220 --> 01:11:29.620

Participant 20: even the abbreviation. Sometimes it's got a hyphen in it, sometimes it doesn't, but the agreement was to

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01:11:29.860 --> 01:11:52.389

Participant 20: create cohesion among the guidance out there, and in the industry and understanding like we needed to stick with one term and plain language. Summary of publication is the most accepted term and best understood people are more familiar. Now, if you say Plsp, they're not scratching their heads anymore. You know a good bit

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01:11:52.520 --> 01:11:57.270

Participant 20: in within the publication, professionals, realm understand what it is.

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01:11:57.390 --> 01:12:02.899

Participant 20: And in that guidance, though I think we've worded in a way to say it's not the only

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01:12:03.320 --> 01:12:24.880

Participant 20: thing that that Standalone. Plain language summary can be called. For example, Adas does theirs as summaries of research articles, but theirs are also geared toward healthcare professionals, and (name) was, is involved in that group, and she's been incredibly great at keeping us from not being exclusionary of any other type of

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01:12:25.150 --> 01:12:44.470

Participant 20: plain language. Publication, summary that would fall into the same thing. As you know. It's a standalone pls, but may not be called a Plsp. But we would hope that other publishers, rolling out that type of publication would use the same terminology, and that helps us, in our case with pubmed to get plsp

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01:12:44.470 --> 01:12:44.900

Karen Gainey: Yes.

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01:12:44.900 --> 01:12:52.159

Participant 20: You know, establishes an article type, and the more that they're established as an article type that's here to stay. I think

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01:12:52.830 --> 01:13:05.229

Participant 20: these other publishers that are really anti plsp, just aren't going to have a choice down the road, I mean, when we say No, you can't. You can't do a systematic review. No, you can't write original research. You can't say that anymore.

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01:13:05.440 --> 01:13:15.289

Karen Gainey: It becomes as part of the it's ingrained like a systematic yeah, methodology. Right? Yeah. Great

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01:13:15.290 --> 01:13:23.749

Participant 20: Plain language. Summaries are further ahead, but plsp are right behind, and I I think that's the chosen term going forward

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01:13:24.250 --> 01:13:25.020

Karen Gainey: Right.

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01:13:25.730 --> 01:13:27.350

Participant 20: That answer your question.

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01:13:27.350 --> 01:13:32.180

Karen Gainey: It does so very quick. Where would you like to see the future of this area?

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01:13:33.850 --> 01:13:35.649

Participant 20: Oh, really quick!

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01:13:37.250 --> 01:13:41.729

Participant 20: I just want every patient that is looking for

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01:13:42.180 --> 01:13:46.229

Participant 20: research to be able to find a plain language summary, or some

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01:13:46.760 --> 01:13:57.090

Participant 20: fine, and I want anybody who's looking for research to be able to find it written in a way they can understand it if that makes sense. And I think

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01:13:57.300 --> 01:14:17.419

Participant 20: I want to stop the spread. What I want is to move forward and have more good information out there than miss and disinformation, and maybe I'm completely crazy to ever think that's a possibility. But I think what we're doing with this work with plain language summaries is taking us to a place where we are putting

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01:14:17.420 --> 01:14:36.650

Participant 20: good information in the hands of the people that are looking for it, or that are out there reading it. And, as I've said before. I think, as publishers, we have a huge responsibility to make sure that's happening and making it accessible. I think accessibility is just. My big thing is making research accessible to people.

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01:14:36.690 --> 01:14:37.560

Participant 20: And

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01:14:37.640 --> 01:14:44.219

Participant 20: because I always say because people talk about. And you probably get this to talk about patience is like, we're like this group of people that like

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01:14:44.710 --> 01:14:56.489

Participant 20: patients. And it's like, No, we are all patients in one way or the other. You go to your doctor once a year. You're a patient. We might. There might be different levels of patients. But patience is inclusive of all of us. So

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01:14:56.490 --> 01:14:56.810

Karen Gainey: Yep.

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01:14:57.510 --> 01:15:01.950

Participant 20: When you're talking about patients, don't treat it like it's some

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01:15:02.620 --> 01:15:05.220

Participant 20: other group of people. It's it's us

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01:15:05.470 --> 01:15:06.390

Karen Gainey: Or no, and they

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01:15:06.390 --> 01:15:07.190

Participant 20: Family.

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01:15:07.190 --> 01:15:07.540

Karen Gainey: Okay.

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01:15:07.540 --> 01:15:07.980

Participant 20: Right.

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01:15:07.980 --> 01:15:08.380

Karen Gainey: Yeah.

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01:15:08.380 --> 01:15:31.879

Participant 20: To your friends. It's you've. If your mom is ill, you want to be able for her to find information online that she can understand, and so that she gets the best treatment possible immediately. I use that because my husband lost his mom to glioblastoma in 5 weeks from diagnosis to death, and it blew us out of the water like

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01:15:31.950 --> 01:15:40.990

Participant 20: how fast it happened. And in that 5 weeks, like the amount of time we spent researching and looking for answers, and I felt

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01:15:41.140 --> 01:15:46.459

Participant 20: she was lucky because she had the support system and had people around her that could guide her

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01:15:46.880 --> 01:15:47.240

Karen Gainey: And

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01:15:47.240 --> 01:15:48.010

Participant 20: Things.

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01:15:48.190 --> 01:16:02.730

Participant 20: People should always have that type of access to information, so they can make the best decisions because as quickly as possible. That was a really long, winded way of saying it. I don't know how to pull that together concisely

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01:16:02.730 --> 01:16:07.750

Karen Gainey: You have passion for this, and I could steal you and talk to you all night, and I'll

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01:16:08.280 --> 01:16:13.000

Karen Gainey: grateful you've given me so much time and energy and your brain

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01:16:13.000 --> 01:16:25.809

Participant 20: If you need any more, I'm more than happy to jump on another call. If you have any more questions or by email, answer anything and anything else you're working on. I love doing this so

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01:16:25.970 --> 01:16:29.700

Participant 20: anything I can do to help those involved in.

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01:16:29.970 --> 01:16:34.320

Participant 20: you know, making this better, for everyone is really important to me.

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01:16:34.650 --> 01:16:37.370

Karen Gainey: Well, thank you. If you can keep me in the loop with what you

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01:16:37.370 --> 01:16:37.860

Participant 20: We're doing

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01:16:38.250 --> 01:16:40.435

Karen Gainey: Yeah, that would be amazing. Because

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01:16:40.800 --> 01:16:41.940

Participant 20: Absolutely. I mean

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01:16:41.940 --> 01:16:51.740

Karen Gainey: It faces writing right now. So anything new and happening, I want to put as much in real life as possible. That's so awesome

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01:16:51.740 --> 01:16:55.289

Participant 20: I'll keep you up to date on happenings as they happen

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01:16:55.530 --> 01:16:58.680

Karen Gainey: Brilliant. Thank you. So thank you much. Again. Take care

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01:16:59.060 --> 01:17:01.230

Participant 20: You, too, take care! Bye.