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00:02:37.591 --> 00:02:51.620

Karen Gainey: obviously, you're you have an editorial role, but it sounded like you were involved in this area with your patients or in your medical role as well or.

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00:02:51.620 --> 00:03:07.440

Participant 11: Or is that not? Not that. So that's a very interesting point. So so I you know, I get on very well with my patients. And and I do try to you know, to interact. You make it, you know, a 2 way interaction.

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00:03:07.870 --> 00:03:37.659

Participant 11: And very often that will necessitate, I'm explaining, sometimes quite complex, or at least complicated issues with the patient. So that's part of my DNA these days working in self-care. And I've only started this work about over the past 6 months or so that also necessitates patients understanding what they're doing and why they're doing it, and so forth.

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00:03:37.988 --> 00:03:55.409

Participant 11: And it's but it's kind of a given. I think we kind of assume that patients are going to understand this, this stuff and that we should tell them. And they can we? Just we do our bit. And then the responsibility is for them to do their bit, which includes comprehending

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00:03:55.420 --> 00:04:24.079

Participant 11: what we're saying to them. And I think that in my role as a clinician, and and now, more recently in my work, working more closely with self-care. Self-care is involved in all areas of medicine, of course, right? The way from just getting somebody to take a pill without self-care right the way through to, you know. Go for a walk and lifestyle, or whatever it might be. So so it's something that we that we all practice or should practice

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00:04:24.356 --> 00:04:35.139

Participant 11: but of course your research is going to go to the heart of you know, perhaps, why some people don't practice as much as they can, and what the challenges are from the patient's perspective, and and so forth.

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00:04:35.800 --> 00:04:38.070

Karen Gainey: Yeah, yeah, I hope so. Yeah, yeah, for sure.

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00:04:38.070 --> 00:04:52.020

Karen Gainey: So I'm keen to dig more into all of that. But I before we go. I further, I should just as a reminder. Remind you, we're recording this session. Just the audio and zoom.

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00:04:52.020 --> 00:04:52.420

Participant 11: It will.

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00:04:52.420 --> 00:04:55.010

Karen Gainey: Provide a transcription, and excellent.

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00:04:55.010 --> 00:05:06.860

Karen Gainey: If if at the end I'll remind you again, if you'd like to have a copy of that raw transcript you're very welcome to. If you feel there's anything you think you'd like to clarify.

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00:05:07.690 --> 00:05:12.770

Karen Gainey: provide additional context for, you're very welcome to, but I feel obliged.

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00:05:12.970 --> 00:05:13.720

Participant 11: Got it. Thank you.

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00:05:13.720 --> 00:05:14.235

Karen Gainey: Yeah.

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00:05:14.750 --> 00:05:21.449

Participant 11: Thank you, Karen, in a sentence. Can you outline your background? Please just let me know what your role.

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00:05:21.830 --> 00:05:32.560

Karen Gainey: Yeah, definitely, just I, just before I forget, I just wanna make sure. If you need a break or something comes up at your end. Just let me know. Or if you need to stop.

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00:05:33.234 --> 00:05:40.969

Karen Gainey: There's no problems there. Yeah, so definitely. So this is the last project. Of my Phd.

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00:05:41.230 --> 00:05:49.929

Karen Gainey: My undergraduate background is in human nutrition and dietetics. But I haven't been involved in that field for a very long time.

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00:05:50.180 --> 00:06:02.759

Karen Gainey: I got interested in this area because I saw so much misinformation in social media groups and just decided I would tackle it and

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00:06:04.130 --> 00:06:32.630

Karen Gainey: fell into this out of a desire to try and do something. So this is my. So I started with a scoping review of the author. Instructions for writing plain language. Summaries followed that up with a, I guess, a compliance audit to compare the plain language summaries with the actual instructions, writing them to see how closely they were aligned, and found

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00:06:32.640 --> 00:06:37.909

Karen Gainey: very variable results. Some journals did very well, some not so good.

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00:06:37.910 --> 00:06:38.840

Participant 11: Yeah, yeah.

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00:06:39.460 --> 00:06:47.529

Karen Gainey: Yours wasn't wasn't included. but that was really interesting.

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00:06:49.330 --> 00:06:50.930

Participant 11: Yeah, so that's just in public.

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00:06:50.930 --> 00:07:20.800

Karen Gainey: (journal), and I've just got I've just sent back my peer review response to a paper I did, asking, I guess people who read plain language summaries. We focused on people with chronic medical conditions because they are high users of health information. We asked them much like, I'm asking you now this sort of interview, what they think is important. Why, they read them a whole range of

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00:07:21.240 --> 00:07:32.130

Karen Gainey: of questions. So I've put all of that together. Now I want to understand from the publishing side how things work in the decision-making sense

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00:07:32.240 --> 00:07:42.520

Karen Gainey: any barriers to implementation. Any facilitators and just thoughts and perspectives on

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00:07:42.960 --> 00:07:47.310

Karen Gainey: we how things are are going, and look to the future to see where.

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00:07:47.310 --> 00:07:47.630

Participant 11: Bridge.

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00:07:47.630 --> 00:07:48.930

Karen Gainey: That that might.

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00:07:48.930 --> 00:07:49.320

Participant 11: Right.

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00:07:49.320 --> 00:07:51.490

Karen Gainey: So. So

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00:07:51.790 --> 00:08:03.900

Karen Gainey: if you've had any editorial experience other than your current journal, please feel free to draw on that also. Don't have to be restricted to your current role.

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00:08:04.550 --> 00:08:07.610

Karen Gainey: But yeah, does that that make sense.

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00:08:07.610 --> 00:08:11.509

Participant 11: It does make sense. If I may ask one question, one question just about social.

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00:08:11.510 --> 00:08:12.489

Karen Gainey: If you like.

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00:08:12.490 --> 00:08:35.939

Participant 11: Thank you very much. Thank you. So you know, when I look at social media and I do this, I do this very regularly these days. You know, I kind of see kind of almost 4 quadrants of information being provided by the general public. Let's assume that they're the general public, and it seems to be those that are communicating very effectively those that are communicating quite poorly

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00:08:36.090 --> 00:08:57.979

Participant 11: those posts that have accurate information, and those posts that have inaccurate information. And so it is quite interesting to see that, or to note that sometimes people communicate can communicate very, very effectively and very, very beautifully and very clearly the wrong information.

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00:08:59.570 --> 00:09:05.130

Karen Gainey: I know exactly what you're trying to say. Yes, you need both, don't you? Accuracy and clarity.

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00:09:05.390 --> 00:09:21.349

Participant 11: That's right, and sometimes that can be more dangerous. So sometimes-sometimes you know the the accuracy or the other clarity of of communication. but I guess it can work both ways, you know, from health. We're not always perfect in their in their knowledge.

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00:09:22.674 --> 00:09:37.009

Participant 11: Sometimes the more eloquent and clearer they are, the higher the risk there is. If if the knowledge component is inaccurate or or you know, not quite on point.

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00:09:37.160 --> 00:09:38.569

Participant 11: But yeah, I just.

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00:09:38.570 --> 00:09:49.749

Karen Gainey: Yeah, I love that. I can see that as a as a grid with 4 4 parts. Yeah, yeah. High clarity, low clarity, high accuracy.

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00:09:49.750 --> 00:09:55.700

Participant 11: High knowledge, low knowledge. Exactly right. It's important this, that this works both ways, because, you know.

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00:09:55.700 --> 00:10:17.959

Participant 11: with my experience, I lecture to clinicians as well and and sometimes, you know, I've not questioned. Well, I was about to say I'm not questioning their motives, but sometimes the influences on clinicians, as we know, can be quite. You know. Cochrane works with this, of course, in terms of bias and so forth. Sometimes clinicians can

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00:10:18.180 --> 00:10:31.039

Participant 11: inadvertently communicates a strength of evidence that's not there, but they might feel it is because they've attended a workshop, or whatever it is, sponsored by a certain party, and and so forth.

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00:10:31.040 --> 00:10:31.380

Karen Gainey: Yes.

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00:10:32.140 --> 00:10:35.560

Participant 11: So, yeah, very very interesting. Very interesting. Yeah, yeah.

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00:10:35.560 --> 00:10:36.660

Karen Gainey: Yeah, no, definitely.

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00:10:36.660 --> 00:10:37.159

Participant 11: Okay. Thank you.

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00:10:37.160 --> 00:10:49.939

Karen Gainey: And so, yeah, I'm really keen to hear your perspectives, because your journal as well. It's it's quite specific. So I want to. Quite a

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00:10:50.230 --> 00:10:53.079

Karen Gainey: is. Your background, I understand, is X

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00:10:54.173 --> 00:10:55.116

Karen Gainey: Disease.

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00:10:56.180 --> 00:10:57.350

Participant 11: So.

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00:10:57.650 --> 00:11:01.270

Karen Gainey: You're, I guess, engaging with a very specific cohort.

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00:11:01.958 --> 00:11:04.350

Karen Gainey: In terms of the audience.

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00:11:04.988 --> 00:11:08.221

Karen Gainey: Yeah. So I mean that that's

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00:11:09.190 --> 00:11:17.430

Karen Gaine: already. That makes your your journal quite distinct. General.

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00:11:17.430 --> 00:11:26.159

Participant 11: I'm yeah. I'm going to clarify that by saying that some journals might be

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00:11:26.210 --> 00:11:41.859

Participant 11: very specific with regard to their audiences. So I don't know, you know (journal) is unlikely to be read by either members of the public, generally speaking, or general physicians or clinicians.

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00:11:42.363 --> 00:12:04.519

Participant 11: Whereas, whereas our journal is, although it's a specialized journal in (speciality). There is an editorial intention that it should be accessible by, I'm afraid not the not the public. We've had debates about that which we can discuss, but certainly other medical disciplines.

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00:12:04.540 --> 00:12:06.100

Participant 11: because- because so yes.

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00:12:06.100 --> 00:12:25.499

Participant 11: some topics, if you like, within medicine, will affect others more so than than other topics will, and I think (speciality) is quite, quite wide ranging. I mean, you can find (specialists). There's a little bit of overlap there. You know, oncology. Sometimes the medications that are taken.

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00:12:26.475 --> 00:12:30.854

Karen Gaine: Right. Yes, that makes that makes sense.

100

00:12:31.920 --> 00:12:43.157

Karen Gaine: I I just can't. Can't recall the term your journal uses for the the type of like a plain language summary, is it?

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00:12:43.590 --> 00:12:46.720

Participant 11: We? We don't. We don't have. We don't have a there's no.

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00:12:46.930 --> 00:12:49.470

Karen Gainey: That'll be right, which some of them I didn't write it down.

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00:12:49.880 --> 00:12:52.830

Participant 11: That'll be, why, yeah, yeah, okay.

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00:12:53.308 --> 00:13:03.129

Karen Gainey: Alright. Well, maybe just to to start I mean, I've got a series of questions and topics I want to cover, but we don't have to. I don't.

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00:13:03.518 --> 00:13:06.489

Participant 11: I want to kind of keep this as free flowing as we can.

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00:13:06.490 --> 00:13:06.960

Participant 11: Yeah.

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00:13:06.960 --> 00:13:33.290

Karen Gainey: I like. I find it always helps. If you can, maybe just give me a snapshot of your role, and how things kind of work with your journal, and I couldn't work out who the publisher is, because one of the things I'm trying to understand is that relationship between the editorial, the journal and the publisher. So I know that can impact decisions. So are you a society journal

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00:13:33.490 --> 00:13:34.150

Karen Gainey: or.

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00:13:34.150 --> 00:13:47.900

Participant 11: So it's so it's a a journal that's that is connected with the with the (Society) So it's an International English language journal.

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00:13:48.000 --> 00:13:53.040

Participant 11: but the the affiliation is with the (Society)

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00:13:53.270 --> 00:14:14.379

Participant 11: in terms of the publisher. I mean, that would be the the the editors realm. Really, we wouldn't really get involved in that editorial meetings wouldn't really? I mean, it's a specialist medical publisher, but it's not, you know.

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00:14:46.000 --> 00:14:48.529

Karen Gainey: I figured it was a society.

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00:14:48.530 --> 00:14:50.149

Participant 11: Yeah, that's right.

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00:14:50.650 --> 00:15:13.969

Participant 11: I think that both the Society and the publishers allow the editorial board to have a pretty wide discretion on what is published, you know. I don't think either the Society, which is obviously another association, or the publishers have any editorial say, that's certainly not been mentioned in editorial meetings.

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00:15:14.420 --> 00:15:26.793

Karen Gainey: Yes, that makes sense. And that's consistent with what I found elsewhere. Yeah, no, that's that's great. I appreciate that. So yeah, just wanted to clarify that. So I understand.

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00:15:27.180 --> 00:15:27.530

Participant 11: Thank you.

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00:15:27.530 --> 00:15:28.820

Karen Gainey: Kind of framework.

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00:15:29.225 --> 00:15:31.789

Participant 11: Yeah, I'll turn it. Turn it over to you.

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00:15:31.930 --> 00:15:58.820

Participant 11: Right? Okay. So well, I serve as one of one of the senior consultant editors on this particular journal, I mean, I sit on. I sat on a number of journals. But this current journal that's that's my, that's my position. It's an International board, an international editorial board. As we've mentioned, it's primarily focused on (speciality).

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00:15:58.820 --> 00:16:20.420

Participant 11: but covers other different disciplines and topics. So in the latest edition, for example. There are, you know. It's a hot theme at the moment, isn't it? AI. So it's, you know. The lead editorial is all about AI and (specialty). And so in that sense it doesn't. I think it tries to appeal to quite a broad audience.

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00:16:20.830 --> 00:16:37.390

Participant 11: Have an interest in in (speciality), but it will include themes that aren't only related to (speciality). I'll talk in a moment about the about the discussions that we had with regard to

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00:16:38.986 --> 00:16:41.730

Participant 11: you know patient summaries, right?

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00:16:41.730 --> 00:16:50.223

Participant 11: But but you know my my sense of the journal is that the is that the is that

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00:16:51.050 --> 00:17:03.200

Participant 11: I'd say. Probably I don't know. Probably 20% of the of the article. I mean, this is just obviously my own opinion, but I would say 20% of the articles would be of interest

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00:17:03.350 --> 00:17:19.719

Participant 11: by patients, by (speciality) patients, and and could be readily read and understood by a patient with with an with an interest which means a motivation

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00:17:19.859 --> 00:17:29.212

Participant 11: to get through the article and and a and an education.

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00:17:32.040 --> 00:17:36.409

Participant 11: I'm just thinking, probably probably undergraduate level, I should think.

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00:17:36.410 --> 00:17:36.750

Karen Gainey: Yes.

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00:17:37.154 --> 00:17:42.160

Participant 11: I would. I would say, Yeah, should I keep going.

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00:17:42.340 --> 00:17:59.839

Karen Gainey: Yes, maybe I'll interject. Would it surprise you if I said that? How many did I interview 19 people I spoke to? Would it surprise you if I said 18 of those had at least an undergraduate degree.

137

00:18:00.360 --> 00:18:03.729

Participant 11: Oh, right? Oh, oh, right. Oh, that's interesting, all right.

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00:18:04.060 --> 00:18:04.440

Participant 11: Right? Okay.

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00:18:04.440 --> 00:18:05.100

Karen Gainey: And 3.

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00:18:05.100 --> 00:18:05.509

Participant 11: I put.

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00:18:05.510 --> 00:18:07.200

Karen Gainey: Graduate degrees.

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00:18:07.200 --> 00:18:10.369

Participant 11: Yeah. Oh, right? Okay. Right? Okay, very interesting. Very interesting. Yeah.

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00:18:10.370 --> 00:18:26.230

Karen Gainey: So that sounds exactly like what you're suggesting whilst we didn't. I wish I'd known what to expect. I would have had an official measure of health literacy using a standardized validated tool at the start.

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00:18:26.740 --> 00:18:32.890

Karen Gainey: But I expected it would be so so broad as to not yeah of such small numbers.

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00:18:33.010 --> 00:18:35.300

Karen Gainey: but I was staggered.

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00:18:35.804 --> 00:18:36.069

Karen Gainey: So

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00:18:36.070 --> 00:18:42.240

Karen Gainey: it seems very clear. There's a type of cohort of people that are attracted to plain language summaries.

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00:18:42.560 --> 00:18:50.640

Karen Gainey: Well, it's suggestive of that. So that's what I'm trying to understand. And it sounds like that's your observation as well.

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00:18:51.001 --> 00:19:06.899

Participant 11: Absolutely, although I would add to that. And this is this is, of course, is another personal opinion, and that is, you know, when I. When I see patients, I can see patients, of course, of all ages, both sexes, the abroad educational backgrounds

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00:19:06.920 --> 00:19:35.700

Participant 11: and and and I do. I do sympathize for those patients who might feel excluded by virtue of not, you know, achieving even an undergraduate level of education because they're not stupid people very often. And it's it's I mean, sometimes they are. To be quite frank, sometimes their level of literacy is so low that they would. They would struggle. That doesn't mean that they're not absolutely

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00:19:35.700 --> 00:19:57.030

Participant 11: beautiful people and not, that's not. It's not obviously not a value judgment. It's just to say that if one were to expect or to write a patient, you know patient summary for them. It would be on occasion. It would be targeted almost as a kind of like a an adolescent level of of literacy.

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00:19:57.424 --> 00:20:17.930

Participant 11: That can both be in terms of you know, grammar, you know. Use of use of words, you know. you know, type of words used and the nature of the the subject in order to try to to to craft it so that it's digestible, so to speak.

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00:20:18.665 --> 00:20:20.750

Participant 11: But I think that there are.

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00:20:20.750 --> 00:20:25.289

Karen Gainey: Imagine. So I imagine that goes beyond just removing jargon.

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00:20:25.550 --> 00:20:26.190

Participant 11: Absolutely

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00:20:26.190 --> 00:20:40.240

Participant 11: absolutely. Yeah. I'm not sure. I mean, there's not actually, there's not really much. There's very little within a medical journal in my experience that that clinicians would label as jargon, you know. But of course, scientific speak

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00:20:40.510 --> 00:21:03.330

Participant 11: is, of course, job for other people. So it's that's that's an interesting question. It kind of goes back to this, this lovely, you know the kind of 1958 reef lecture, the clash of cultures, you know, when it was, you know, it talked about these kind of 2 people, the arts, people and the sciences, people who couldn't really communicate with each other because they were essentially talking different languages.

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00:21:03.330 --> 00:21:14.789

Participant 11: And and I think that's you know, that's the case. Today. I think that you know essentially scientific journals, which is what medical journals ostensibly are about

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00:21:15.178 --> 00:21:29.569

Participant 11: sometimes struggle because of the you know, the jargon to to achieve communication with people who are simply not used to that. They might be more arts focused. So these, though that type of person

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00:21:29.954 --> 00:21:46.469

Participant 11: could could, of course, be highly educated and articulate, and still not really understand, any more than the person with with less education. And that's a shame as well. And that's the challenge, really, isn't it? To to try to I mean.

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00:21:46.470 --> 00:22:06.979

Participant 11: you know, with, in a sense, when I look at patient summaries by the way, we worked on this at (journal) actually, coincidentally, on this particular theme to cover this and the conclusion that we came to, and this was when trying to provide patient information to pregnant women

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00:22:06.980 --> 00:22:19.490

Participant 11: and and we kind of came to the conclusion that that it would be quite a quite, quite a sophisticated technical approach would be required in order to bridge this gap.

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00:22:19.490 --> 00:22:26.020

Participant 11: because otherwise, essentially, one might simply be producing

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00:22:26.500 --> 00:22:46.525

Participant 11: 2 versions, just 1 1 version that we call for the clinicians. And and you know, 98% of clinicians will understand it, and another patient summary that might only be understood by 50% of the patients. So because there are so so many potential variances in the in the

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00:22:47.461 --> 00:23:06.750

Participant 11: in the in the text. Now, if I can, just very, very quickly, is just just say that as with all of us. We can all get turned off very quickly by things you know we we have this very, you know, vast need, you know, for clip, bait, and so forth. And I think it's the same with medical or health

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00:23:06.750 --> 00:23:29.810

Participant 11: topics, you know, if people aren't engaged interested and the obverse, you know, if if they don't feel as though they're being pushed away by the jargon or by the theme, or on so forth, you know, I think it's quite difficult to get people to just plough on and continue, and to to try to give them the confidence that if they stick

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00:23:29.810 --> 00:23:47.129

Participant 11: it'll be worth it by the by the end, because very often I've had that situation whereby sometimes I've gently, and you know, in a friendly manner, really tried to encourage somebody to read something that I've wanted them to understand, and they've come back, and they've claimed to have read it. And I've you know you know

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00:23:47.270 --> 00:24:02.400

Participant 11: I haven't believed them, and they've gone off, and they've come back the next time, and they and they've and they've and they've read it. And they said, Thank you. You know that was a you know. I suck at it. I didn't really get the 1st bit or the last bit, but the middle bit was actually quite useful. And that's how

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00:24:02.690 --> 00:24:04.450

Participant 11: that's something.

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00:24:04.560 --> 00:24:06.470

Karen Gainey: Yeah, that we can build on that.

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00:24:06.880 --> 00:24:10.649

Karen Gainey: No sorry. I said. That's great. You can build on that.

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00:24:10.650 --> 00:24:11.410

Participant 11: Yes.

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00:24:11.970 --> 00:24:12.450

Karen Gainey: Yeah.

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00:24:12.450 --> 00:24:36.160

Participant 11: Yeah, exactly right. Yeah. But how that? How that can be, you know that. There, I mean, there are ways of, you know. I don't think one needs to involve Elon Musk in something like that. I don't think it's that big a technical challenge, but you know, I think that it does need to be so. I did. I think it does need to be considered, because otherwise the best one in the world, as I say, you know, by by grandly producing this patient summary.

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00:24:36.160 --> 00:24:46.719

Participant 11: You can disenfranchise some people and and give them even less confidence. I don't even understand the patient summary.

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00:24:47.290 --> 00:25:07.919

Participant 11: and that can, as I say, as as mentioned, that can that can. That can be the case both for for people with lower education and people with a higher education, you know. I never forget the time I had a conversation once with with with with with a patient in primary care on a on a heart related to heart rate, related topic.

177

00:25:08.000 --> 00:25:23.029

Participant 11: and I was talking to him about this stuff and and and then he he repeated what I said in very simplistic terms, and I thought, Gosh, that's fantastic, that's a great summary. And he was an engineer.

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00:25:23.440 --> 00:25:24.700

Participant 11: so he couldn't rock.

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00:25:24.700 --> 00:25:45.019

Participant 11: He couldn't really understand what I was saying, and I was saying everything. You know the best way that I could in a scientific medical health related way. But for him. It wasn't that he needed simpler language. It's just he needed a language that was kind of consistent with the way he understands the world.

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00:25:45.660 --> 00:25:47.290

Karen Gainey: Way his brain worked. Yes.

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00:25:47.629 --> 00:25:48.309

Participant 11: Exactly right.

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00:25:48.310 --> 00:25:58.080

Karen Gainey: Yeah, yeah, that's extremely consistent with what I found. And one of the themes that came through building on what you said was.

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00:25:58.450 --> 00:26:09.819

Karen Gainey: how important, the we're talking about patient summaries, or, if I use the word plain language summaries, I'll use it very generically to refer to all these type of summaries.

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00:26:09.820 --> 00:26:10.390

Participant 11: Yeah.

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00:26:10.770 --> 00:26:14.600

Karen Gainey: Aimed at non-experts. Shall we say?

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00:26:16.300 --> 00:26:31.989

Karen Gainey: one of the things that came through was, how important that label is, or that title I don't mean the title of the the summary. I mean that label, whether it's plain language, summary, patient, summary lay summary, and

187

00:26:32.120 --> 00:26:42.939

Karen Gainey: the word lay evoked quite strong emotions. Some people said that it has religious connotations. It reminded them of chickens.

188

00:26:43.783 --> 00:26:44.306

Participant 11: Like.

189

00:26:46.300 --> 00:26:47.680

Karen Gainey: We wanted.

190

00:26:49.640 --> 00:26:50.990

Participant 11: Or it just.

191

00:26:51.200 --> 00:26:55.050

Karen Gainey: Was just a strange word. Some people didn't patient.

192

00:26:55.250 --> 00:27:04.819

Karen Gainey: Some people don't like the consumer. Some people really found the word patient, warm, and friendly. So it was really.

193

00:27:05.210 --> 00:27:14.659

Karen Gainey: however we looked at it. It had a strong reaction, and with some people was a determining factor. Whether they read the summary itself or not.

194

00:27:15.360 --> 00:27:15.830

Karen Gainey: City.

195

00:27:16.230 --> 00:27:19.070

Karen Gainey: Yeah, it was so so influential.

196

00:27:19.520 --> 00:27:39.790

Participant 11: I think that's great. Yeah, I think that's absolutely brilliant. And I can absolutely say increasingly, people don't like to be seen as as labeled as as patients. Some people do. I mean, that's that this goes back to the patient syndrome whereby people want to be looked after. They want to be told what to do, and and so forth.

197

00:27:39.790 --> 00:27:59.619

Participant 11: The lay one is very interesting. Some patients know more than their doctors about their conditions, very often diabetics. For example, if you compare a lay diabetics knowledge of diabetes, you know. If that person had diabetes for 10 years, for example, compared with a new Gp.

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00:28:00.053 --> 00:28:00.789

Participant 11: I mean, you know.

199

00:28:00.850 --> 00:28:01.600

Karen Gainey: Exactly.

200

00:28:01.600 --> 00:28:24.479

Participant 11: That's not a lay, and I think the and the 3rd thing I would say is that plain language? I think you're absolutely right about that I need to stop calling it patient

summaries. It is plain language. The reason, I say that is because one of the themes that came up with our discussion of plain, of plain language summaries was the need for some doctors from different disciplines to be able to understand the material as well.

201

00:28:25.115 --> 00:28:25.510

Participant 11: Yep.

202

00:28:25.510 --> 00:28:26.770

Karen Gainey: Yeah, yeah.

203

00:28:26.770 --> 00:28:38.019

Participant 11: And I know for a fact, because I do it myself. I will very often with a Cochrane Review, and if it's a particular topic that I don't know much about. I will at least start with the plain language summary, which I find tremendously useful

204

00:28:38.020 --> 00:28:38.949

Participant 11: if I get.

205

00:28:38.950 --> 00:28:52.210

Participant 11: and it's interesting, it might pull me into the bigger text. And that's 1 of the conclusions we came to at (journal). Actually, that the information, the delivery of information one way around. This might be to layer it, to try to to

206

00:28:52.210 --> 00:28:55.206

Participant 11: join me, so that people are gradually invited in

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00:28:55.560 --> 00:28:56.170

Karen Gainey: Yes.

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00:28:56.170 --> 00:28:57.260

Participant 11: To the text, yeah.

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00:28:57.600 --> 00:29:12.790

Karen Gainey: That's what people reiterated as well, because we spoke to people with chronic medical conditions. They're often using it to inform themselves of new innovations or discoveries about their existing condition.

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00:29:12.960 --> 00:29:36.170

Karen Gainey: and wanted the summary to give them that takeaway actionable information to help them determine is the article something I would want to read, to get a bit more detail about? Or does it not apply to me at all? Or is it something I would want to take to my doctor and have it open. A discussion about is this new thing right for me?

211

00:29:36.270 --> 00:29:44.999

Karen Gainey: So it was incredibly important to get that information to them, because they really were invested in using it.

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00:29:46.390 --> 00:29:55.139

Karen Gainey: So where did you? Where did you land at (journal) with that decision about implementing.

213

00:29:55.320 --> 00:29:55.890

Participant 11: This.

214

00:29:55.890 --> 00:29:56.570

Karen Gainey: Kind of summary.

215

00:29:56.570 --> 00:30:01.350

Participant 11: So before I answer that question, can I just raise another point? Can I just ask you a second?

216

00:30:01.480 --> 00:30:20.699

Participant 11: And that's just have you done any work, or do you have any sense of the of the nature of the you've described it as plain language summary, for example, and that's great, and then you go to the next layer, which is the title of the actual article. And do you have any? Is this is this part of the scope of your work.

217

00:30:20.700 --> 00:30:43.490

Participant 11: because that's something. I remember us discussing the difference between between the patients will have different needs, and they have different personalities, and so forth, and some are very serious, and their illness is very serious, and they want to. They want an answer, and that's the reason they're reading the article.

218

00:30:43.490 --> 00:31:04.220

Participant 11: and others will be perhaps a little bit more relaxed, will be doing it more for interest or as much for interest. As for the value it will be able to provide in terms of their

thing. So, on the one hand, it's possible to go for a you know, with a consistent title, the same title as the medical article. But this is the plain language summary of that.

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00:31:04.220 --> 00:31:12.523

Participant 11: and, on the other hand, you know, one can opt for the the the kind of click baity,

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00:31:13.710 --> 00:31:17.809

Participant 11: and and of course those 2 are kind of like almost diametrically opposed

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00:31:17.990 --> 00:31:31.479

Participant 11: for people. You know, the people in the relaxed camp don't want to kind of click bait kind of thing, and the people in the serious camp. Don't want to know that the content of the article is going to be more serious than is suggested in the title.

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00:31:32.510 --> 00:31:49.099

Karen Gainey: Yeah, I understand what you're saying it. I think it comes down to well, from from everyone I know. Let me start with what I found when I did the Scoping review which, and have, and in speaking to, I think, about the 11.th

223

00:31:49.500 --> 00:31:52.960

Participant 11: Or 12 person journal editor I've spoken to so far.

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00:31:53.070 --> 00:32:11.729

Karen Gainey: So what we found in the Scoping Review is that most of these kind of summaries are published just under the abstract in the Journal manuscript, so they're not given a separate. So the title is just

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00:32:11.890 --> 00:32:15.430

Karen Gainey: playmaker, summary, patient, summary, or

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00:32:15.941 --> 00:32:25.170

Karen Gainey: or or key. Sometimes their key messages highlights like Elsevier is highlights, so they're not given a title that is linked to the topic of the summary.

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00:32:25.170 --> 00:32:25.720

Participant 11: Yeah.

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00:32:25.960 --> 00:32:38.770

Karen Gainey: Article. Sorry. So I think it's only if they're used on something like social media and shared as just the summary themselves that it would be necessary.

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00:32:39.422 --> 00:32:43.150

Karen Gainey: Which, talking to people very rarely happens.

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00:32:43.320 --> 00:32:45.799

Participant 11: Yes, yes. Yeah. Yeah. I can imagine.

231

00:32:46.040 --> 00:32:50.130

Karen Gainey: I see that as a huge opportunity that's missed.

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00:32:50.130 --> 00:33:17.270

Participant 11: Absolutely. I mean, that would be fascinating to do like an A B study. On looking at the differences between the 2, to see which has more uptake, because the because sometimes patients can read a title. So, for example, if there was a title saying, You know, it's been discovered that the Les Sphincter can improve symptoms in 60% of cases.

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00:33:17.270 --> 00:33:21.510

Participant 11: I mean, people might not know that that relates to heartburn to yeah.

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00:33:21.720 --> 00:33:37.400

Participant 11: it's something that they're kind of aware of, and so forth. This kind of lower esophageal sphincter is is, they wouldn't get that. But if it was, if it said, you know, like 60% of acid reflux sufferers have been, you know, have found that

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00:33:37.660 --> 00:34:05.650

Participant 11: the strengthening of the Nes. They might, they might, they might go that second part, it's very interesting, you know. I think that many plain language summaries might be skipped by people potentially because they've read the title. And sometimes, you know the title of a book does, you know, dictate whether or not somebody goes further or not? But I think that would probably need to be need to be tested. Getting back to your question.

236

00:34:05.650 --> 00:34:08.269

Karen Gainey: I can just build on that. I did just think of something.

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00:34:08.270 --> 00:34:08.850

Participant 11: Yeah.

238

00:34:10.342 --> 00:34:23.400

Karen Gainey: One of the things that is a new kind of or it's not not new in a sense, the future science group when they're around they were doing. Have you heard of plain language, summaries of publications.

239

00:34:23.806 --> 00:34:24.620

Participant 11: Yes. Yeah.

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00:34:24.620 --> 00:34:40.209

Karen Gainey: Yeah. So when that was subsued by (Publisher), they kept that that style. And now Sage have introduced that as well. They have their own DOI, so they can be indexed. Medline.

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00:34:41.260 --> 00:34:47.900

Karen Gainey: I am unsure if they use the same title as the manuscript. They're attached to.

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00:34:48.199 --> 00:34:48.669

Participant 11: That's.

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00:34:48.670 --> 00:35:08.496

Karen Gainey: I do know, but they were a standalone piece, and 4 to 5 pages long. But I do know. Having reviewed several Cochrane reviews which focused on just the plain language summary, and I I know the person who revised their guidelines a couple of years ago.

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00:35:09.780 --> 00:35:12.620

Karen Gainey: that they recommend changing the title

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00:35:13.600 --> 00:35:25.379

Karen Gainey: to plain language, but not veering too far, but definitely changing it. But one thing that participants did tell us was that if it's

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00:35:25.550 --> 00:35:34.460

Karen Gainey: something that's related to a medical condition they have. And so it might be a disease.

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00:35:35.102 --> 00:35:47.490

Karen Gainey: That disease name, isn't. They? Don't consider that jargon, because they particularly if they've had it for a little while. They they know that name. They're familiar with it. So

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00:35:47.640 --> 00:35:52.070

Karen Gainey: it's it's a. It's a really nuanced area.

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00:35:52.070 --> 00:35:53.210

Participant 11: Yeah, no. Absolutely.

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00:35:53.210 --> 00:35:54.860

Karen Gainey: Clear solutions. Yeah.

251

00:35:54.860 --> 00:35:55.310

Participant 11: Yes.

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00:35:55.310 --> 00:36:00.409

Karen Gainey: When it comes to that, and they don't want that removed from the text or the title, because.

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00:36:00.410 --> 00:36:00.810

Participant 11: That.

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00:36:00.810 --> 00:36:03.410

Karen Gainey: Tells them exactly. This applies to me.

255

00:36:03.895 --> 00:36:05.839

Participant 11: Yeah, no, I understand.

256

00:36:05.840 --> 00:36:08.330

Karen Gainey: Becomes really difficult. Yeah, yeah.

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00:36:08.330 --> 00:36:11.749

Participant 11: Very interesting about the really helps. But it's.

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00:36:11.750 --> 00:36:14.189

Karen Gainey: Yeah, I think, just shows how.

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00:36:14.330 --> 00:36:15.800

Participant 11: Complex it is.

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00:36:15.800 --> 00:36:16.120

Participant 11: Yes.

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00:36:16.120 --> 00:36:16.510

Karen Gainey: That's like.

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00:36:16.510 --> 00:36:19.090

Participant 11: Yeah, which makes my face.

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00:36:19.880 --> 00:36:21.230

Participant 11: Yeah, the only issue.

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00:36:21.230 --> 00:36:22.180

Karen Gainey: But anyway.

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00:36:22.370 --> 00:36:22.670

Participant 11: Yes.

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00:36:24.220 --> 00:36:35.869

Participant 11: 1. 1 issue with that, of course, is that the is I'll be interested to know the the the educational, a, the educational level of medline users, which I suspect is probably quite high.

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00:36:35.870 --> 00:36:36.260

Karen Gainey: Like.

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00:36:36.260 --> 00:36:56.209

Participant 11: If they're going to going directly to medline as opposed to to someone who is just using Dr. Google, just just gonna go through, and and because I suspect that the 2

audiences would respond differently to that to that, to that title with the medline users, I suspect.

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00:36:56.210 --> 00:37:07.689

Participant 11: being far more tolerant and forgiving of a of a of a complicated title, and the others having in mind very much in mind what they're looking for.

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00:37:07.750 --> 00:37:27.410

Participant 11: and and if they don't find it getting confused. And I had this yesterday. I was on a Facebook group yesterday, and someone was highlighting the risks of premature ventricular contractions to all cause mortality, and they were referencing a page from 2,007

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00:37:27.410 --> 00:37:40.000

Participant 11: that was relating to heart failure patients. So it was completely. Completely. But they hadn't determined this. It was in the title, but they hadn't even determined that, because they probably thought because they had palpitations.

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00:37:40.000 --> 00:37:42.040

Participant 11: that that was their heart failing

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00:37:42.210 --> 00:37:56.610

Participant 11: so, which is common, obviously a common, a common misunderstanding. So the the titles issue, I think, is it? You can write a thesis on that alone, I suspect. Yeah.

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00:37:56.740 --> 00:37:59.629

Karen Gainey: Yeah. Yes, yeah. 100%.

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00:38:00.070 --> 00:38:02.179

Participant 11: So so getting back to (journal).

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00:38:02.700 --> 00:38:24.059

Participant 11: Yes, so so I it was quite. It was quite useful, actually, because for us, because so what it was. It was project based on a global study that was conducted at (journal) called into growth, and and it was looking to disseminate that that information to pregnant mums around the world. And it was going to be done via an app.

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00:38:24.388 --> 00:38:49.270

Participant 11: Sadly, the project couldn't continue due to covid. So lots of funding and all the rest of it during that. But it was, it went on for quite quite a while, and and the the only answer that we came up with in terms of delivering information. Was a technical one. And we were using psychographics. So we were literally because the because the mother had on on boarded via an app

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00:38:49.280 --> 00:39:09.209

Participant 11: and had already completed a few demographic questions, including educational level. Then we were able to we were able to try to frame that information in an appropriate way. Now the the ambition

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00:39:10.050 --> 00:39:28.490

Participant 11: was to enable her to kind of go up and up or down a scale, so to speak. You know, if she wanted more information she would be able to to get it. A more complicated information to be able to access access that upon upon request rather than just being given

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00:39:28.490 --> 00:39:40.709

Participant 11: the option of going to directly to the source. We were going to give her another option, just to kind of like, go slightly up the scale, as it were. And yeah, and that's so it was a technical solution. Really.

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00:39:40.710 --> 00:39:43.570

Karen Gainey: No, that's a shame!

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00:39:44.610 --> 00:39:51.160

Karen Gainey: That would have been really interesting. And what were your measurements? Were you measuring comprehensibility and.

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00:39:51.160 --> 00:40:20.439

Participant 11: That's right, exactly right? Exactly right? Yeah. So the comprehensibility we were using studies that had that were using educational level and and kind of really guesstimating the because it's very, it's very difficult. It's so. It's so difficult. So, for example, you know, for a pregnant mum, you know, she she gets up in the morning and and you know she has brain fog and literacy level falls to the floor.

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00:40:20.540 --> 00:40:48.739

Participant 11: But by the afternoon, you know, it might be, might be back up to a normal level or even further down. So you know, it's, I think, you know, in terms of of literacy health Literacy. You know, I have found with patients who patients who I've seen consistently for

over a period of time, that their health literacy. I thought I found it very dangerous to to define or seek to define their health literacy, because I feel that it can, or if I have found

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00:40:48.740 --> 00:41:13.270

Participant 11: that it can fluctuate, depending on the time of day. How agitated they are! The topic, the topic under discussion, whether they come in with their partner or not. You know there are so many different factors that will affect. And, by the way, I absolutely know that those variables

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00:41:13.822 --> 00:41:21.650

Participant 11: are taken home as well. So you know the literacy level appears to be, for example, whether it was discussed.

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00:41:21.910 --> 00:41:33.769

Participant 11: you know, with my partner, or when I was reading it independently. You know, if I was having a good time at home, or the children were going crazy, or whatever whatever it might be. So yeah, yeah.

288

00:41:33.770 --> 00:41:39.567

Karen Gainey: That's that's so interesting. That's incredibly useful.

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00:41:40.400 --> 00:41:44.239

Karen Gainey: if you if you come across a reference for that, I'd love it. But I'll have.

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00:41:44.240 --> 00:41:45.710

Participant 11: A look for that.

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00:43:33.900 --> 00:43:43.710

Karen Gainey: Yeah. Yeah. And to be talking to people like yourself, I mean, everyone I've spoken to shares one thing which is a genuine enthusiasm

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00:43:44.650 --> 00:43:45.700

Karen Gainey: area, regardless.

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00:43:45.700 --> 00:43:46.070

Participant 11: One's.

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00:43:46.070 --> 00:43:52.169

Karen Gainey: Happening at your journal is sharing ideology, something that's ideologically driven.

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00:43:52.910 --> 00:43:54.159

Participant 11: And that's something.

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00:43:54.160 --> 00:43:55.650

Karen Gainey: Really trying to.

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00:43:55.650 --> 00:44:00.470

Karen Gainey: Well, not not trying to. I do appreciate, but really

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00:44:00.820 --> 00:44:10.529

Karen Gainey: trying to find how, what are the barriers to translate, relating that into what happens at the journal level.

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00:44:10.530 --> 00:44:11.440

Participant 11: Absolutely.

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00:44:12.779 --> 00:44:13.599

Karen Gainey: Yeah.

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00:44:13.940 --> 00:44:22.219

Participant 11: Yeah, I think it's very good. I think sometimes because I serve them quite a lot of boards. So

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00:44:22.600 --> 00:44:34.569

Participant 11: a lot of both commercial boards, and of course, editorial boards and charity boards, and so forth and on boards. You know, there's quite a lot of kind of form ticking.

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00:44:34.710 --> 00:44:58.139

Participant 11: and I do feel sometimes that journals do do think you know, do treat this topic like it's something that we can do to you know, to maybe you know, get a little bit more funding or or you know, or you know, pacify or satisfy the publishers, or whatever it might be, or the society. Maybe maybe there's some some pressure coming from the society. But

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00:44:58.801 --> 00:45:05.760

Participant 11: I'm very encouraged that there are that other, you know. Good fellow. Editors are can genuinely see that link

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00:45:05.850 --> 00:45:32.109

Participant 11: between between knowledge and and a patient, and and it's and it's just littered with with pitfalls and hurdles. Ice, you know. It's it's very. It's very tricky. for patients. I myself have had patients. I had a bad back for a long time. You know some slipped discs. I have Pvc's myself.

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00:45:32.895 --> 00:45:38.790

Participant 11: and so and so like you, you know, with your (illness), you know I've I've

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00:45:38.790 --> 00:45:49.410

Participant 11: I've walked, I've walked the walk as a patient, and I have had a sample of of the experience, and it's it can be quite shocking.

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00:45:49.970 --> 00:45:53.250

Karen Gainey: Yeah, that makes, since it changes your perspective a lot, doesn't it?

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00:45:53.250 --> 00:45:58.280

Participant 11: Absolutely absolutely. Yeah. The empathy goes through the roof, I think after that.

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00:45:58.280 --> 00:46:07.209

Karen Gainey: Yeah, that makes a lot of sense. Yeah. But I suspect you're probably quite empathetic and tuned in to start with. And that's just added an extra layer.

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00:46:07.550 --> 00:46:28.729

Participant 11: Well, I hope so. I hope so, but you know I must say it's certainly made me more humble, particularly the back pain, you know when one and you will know this with (illness), you know, with them, when people talk, sometimes talk about pain doctors when they talk about pain, they might talk about pain, scale, and and so forth. But to actually experience this kind of pain, this distress.

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00:46:28.730 --> 00:46:29.440

Karen Gainey: Yeah.

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00:46:29.600 --> 00:46:56.090

Participant 11: At an extreme level is very eye-opening. It certainly makes one open minded to any claims, because that's very often what doctors will see, and healthcare professionals will see patients making when they report their symptoms, their claims. Unless we can see the signs of that damage.

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00:48:26.500 --> 00:48:31.869

Karen Gainey: So what do you have any sense of what the barriers are?

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00:48:32.250 --> 00:48:37.129

Karen Gainey: Forget me. Forgive me for not saying your journal. It's a bit of a mouthful.

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00:48:37.960 --> 00:48:52.859

Karen Gainey: Why is it because so many articles are quite easy to understand by, say, patients or end users, that the journal hasn't decided to introduce a specific summary? Or do you think there's other factors.

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00:48:53.400 --> 00:49:03.589

Participant 11: I think that. I think that on many of these journals, including mine, there are too many clinicians understandably.

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00:49:03.590 --> 00:49:25.430

Participant 11: who are domain specific. So ours is a (specialist) journal. It's read by (specialists) or specialists in (medical discipline). Some people can access it, but they're not the intended audience. So you know what this is not really an issue. It's not really a. There are other things that need to be discussed. There are other priorities, and so.

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00:49:25.430 --> 00:49:26.240

Karen Gainey: Priorities.

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00:49:26.240 --> 00:49:52.600

Participant 11: I think that's a little bit short-sighted. I think that having a broader readership, I think, can only help a journal. So you know, I'd like to. But I think that's what holds back our journal and other journals. It's simply not seen as a priority. If it were, there's a certain real estate, of course, on a page.

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00:49:53.180 --> 00:50:05.530

Participant 11: If that's taken up with a patient summary, then that's what does it impact? Does it impact the length of the abstract. Do we have to push the real information to the second page? You know.

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00:50:05.640 --> 00:50:29.440

Participant 11: So I think I think you know I'm a school that all abstracts should be plain language summaries. I don't. I don't think I don't believe in scientific abstracts. I don't. I don't think I don't understand them about Einstein saying, you know, if it can't be, if it can't be

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00:50:29.790 --> 00:50:34.179

Participant 11: explained in simple terms, then the person doesn't understand it themselves, and.

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00:50:34.180 --> 00:50:34.550

Karen Gainey: Yes.

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00:50:34.550 --> 00:50:43.359

Participant 11: There will be some exceptions to that. For example, the highly scientific journals that they, you know, that's for them, the simple is

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00:50:43.360 --> 00:50:43.760

Participant 11: yes.

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00:50:43.960 --> 00:50:58.164

Participant 11: it's different. But I think in terms of (speciality)I mean, it's it's a simple, it's a simple business X disease. It's a simple, it's so simple as a pump with some tubes, you know.

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00:50:58.570 --> 00:50:59.790

Karen Gainey: Logistics.

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00:51:03.540 --> 00:51:05.559

Karen Gainey: It's just a pump, but some tubes.

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00:51:05.560 --> 00:51:27.119

Participant 11: Well, you know, at the end of the day, that's what it is, and I think very often authors and journalists as well, to an extent would rather complicate the articles in order to make them sound themselves sound a little bit more serious.

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00:51:27.120 --> 00:51:27.520

Participant 11: and

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00:51:27.520 --> 00:51:36.489

Participant 11: and so forth, because don't forget that many people on editorial boards are quite senior people, both within the societies and globally, internationally.

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00:51:36.490 --> 00:52:01.320

Participant 11: and I think there is somewhat. There are some exceptions to that, you know. I always think of (name), in the (country) at (Hospital). He works quite closely with the (Association). He's a charming man, and he's always striving to simplify things and make things simple. But he's the exception rather than the rule, I think. Generally speaking, you know, academics can be

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00:52:01.320 --> 00:52:11.970

Participant 11: quite academic, and and to to simplify things is almost seen as a dilution of all their hard work.

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00:52:12.020 --> 00:52:15.076

Participant 11: In my opinion, pulling the work together.

386

00:52:15.480 --> 00:52:16.330

Karen Gainey: I'm with you.

387

00:52:16.330 --> 00:52:45.209

Participant 11: So I think in that sense the journal needs to look at what is the journal's objective? Does it include trying to disseminate information to a broader public, and I would always at that point interject that that broader public includes healthcare professionals as well as lay people. Because if you get a group of there was that lovely quote by an American political editor.

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00:52:45.270 --> 00:52:49.939

Participant 11: who said that he would rather be rather be ruled

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00:52:50.030 --> 00:53:01.539

Participant 11: or governed by the 1st 2,000 people in the in the Massachusetts phone book

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00:53:01.700 --> 00:53:07.429

Participant 11: than than the current 2,000 legislatures who are governing the United States.

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00:53:07.890 --> 00:53:32.330

Participant 11: And it's a lovely one, is it? Yeah, I'll try to find that quote for you. And that basically talks to. You know the wisdom of the crowd, if you like, and the fact that people aren't stupid, and very often people can be can be smarter, sharper, more incisive.

392

00:53:32.380 --> 00:53:55.369

Participant 11: more insightful than clinicians, or the editor, or the editors of journals, or the authors of articles. And so I you know, I think, when with plain language summaries, you know, I think, that you know, as I, as we said at the beginning of our meeting. You know there are many clinicians, healthcare professionals, who don't work in a particular

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00:53:55.780 --> 00:54:05.669

Participant 11: discipline, you know clinical discipline. But but who may need as well as want to understand what is being communicated in that article?

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00:54:06.479 --> 00:54:09.980

Participant 11: And so everybody benefits from from a plain language

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00:54:10.160 --> 00:54:17.649

Participant 11: summary last year. On that point I would say that it should be a challenge set down by the journal.

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00:54:17.880 --> 00:54:28.240

Participant 11: They should say to the authors, you know, if you, if you you've ticked all of our boxes. This is fantastic. Peer reviewed. Everything's wonderful. There's 1 box that one more box that you need to tick.

397

00:54:28.360 --> 00:54:51.310

Participant 11: and that is, you need to provide us with a plain language summary. Whether the journal publishes it or not. It's another matter, but the article need to prove that the article can be communicated to intelligent people who may not be from their own discipline. If it can't, they need to go away. And you know, brainstorm in until they can, in my opinion.

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00:54:51.370 --> 00:55:02.240

Participant 11: So yeah, except for the truly truly deep scientific journals get out of jail record for them. But yeah.

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00:55:02.240 --> 00:55:05.860

Karen Gainey: Every author gets one a year or or

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00:55:06.190 --> 00:55:09.615

Karen Gainey: it gets gets to

401

00:55:10.510 --> 00:55:16.370

Karen Gainey: Yeah, there's a criteria, I know, like, you know, deep genetic things or a technological something? Yeah.

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00:55:17.770 --> 00:55:18.630

Participant 11: Exactly.

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00:55:19.100 --> 00:55:19.659

Karen Gainey: I love that.

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00:55:19.660 --> 00:55:20.180

Participant 11: And.

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00:55:20.180 --> 00:55:25.360

Karen Gainey: It's I mean, when you're speaking it. What jumped out at me is that the dunning-kruger effect.

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00:55:26.030 --> 00:55:27.210

Participant 11: Yeah, yeah.

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00:55:27.210 --> 00:55:27.790

Karen Gainey: Yeah.

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00:55:28.220 --> 00:55:36.922

Participant 11: No, absolutely. We don't know what what? We don't know. Yeah, that's a that's a lovely paper.

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00:55:37.820 --> 00:56:01.590

Participant 11: yeah, that's always stuck with me. I almost went to (University) to study X that was before the paper was published. But I've always had an interest in X, and it is, I'm afraid it's very difficult to find, and A and X are are 2 separate things and too many people, I think.

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00:56:01.590 --> 00:56:14.359

Participant 11: even within this field, looking at plain language. Summaries assume that the 2 are are synonymous. I mean, they're related arguably, but they're not. They're not they're not

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00:56:15.109 --> 00:56:16.309

Participant 11: they're not the same thing.

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00:56:16.810 --> 00:56:27.409

Karen Gainey: Yes. Oh, you've just got some terrific so many quotable things coming out of you, Richard. It's it's all gold. This is absolutely.

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00:56:27.410 --> 00:56:28.560

Participant 11: That's good. Good. Yeah, yeah.

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00:56:28.560 --> 00:56:32.029

Karen Gainey: Well, I don't want to. I don't want to keep you too long, I guess.

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00:56:32.030 --> 00:56:32.410

Participant 11: It's just.

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00:56:32.410 --> 00:56:57.050

Karen Gainey: To wrap up something you touched on right at the beginning, your thoughts on the use of generative AI in this sort of space, and looking to the future as well. Where do you? Where would you like? Let's separate them out. What are your thoughts on the use of generative AI in producing journal publishing and producing these kind of summaries.

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00:56:57.590 --> 00:57:17.046

Participant 11: So. So I am. I am. I am not. I am not aware of the of any technology. If it exists that which can provide a genuine plain language summary of a piece of text. I mean, I've seen these.

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00:57:17.800 --> 00:57:40.280

Participant 11: actually, that's not true. I have. I have seen them on the Internet. One can put in a text and so forth. One can do it with Chat Gpt put in a test result, for example, and ask for it to be explained. And it will be explained. My understanding of the current literature on this is that that still can't be relied upon.

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00:57:40.683 --> 00:57:49.160

Participant 11: Having said that, I use deepseek, and I use chat gpt, I use the pubmed version of chat gpt as well.

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00:57:50.390 --> 00:57:59.939

Participant 11: occasionally including to to to write, or to serve as the basis of patient materials, that I might, I might write.

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00:58:00.815 --> 00:58:01.785

Karen Gainey: However, I

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00:58:02.660 --> 00:58:12.129

Participant 11: I probably spend as as much time on it as I would as I would have done, because what I'm seeking to do in doing that

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00:58:12.230 --> 00:58:20.699

Participant 11: is, not to provide me with the content so much as to provide me with a way of saying the content.

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00:58:20.700 --> 00:58:44.229

Participant 11: So I will go through the the content that's produced, and it will be invariably it will be inaccurate, incomplete, misleading, biased in that one shape or form. It won't be coherent, etc, etc, so I will need to go through it line by line in order to modify it.

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00:58:44.300 --> 00:58:50.769

Participant 11: but I will find it useful. because it will provide me with

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00:58:51.150 --> 00:58:59.200

Participant 11: ways of saying certain things that I'm sometimes. Sometimes I struggle to to think of.

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00:58:59.200 --> 00:59:00.630

Karen Gainey: A starting point.

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00:59:00.630 --> 00:59:20.940

Participant 11: Exactly right, exactly right. I haven't found a way of doing it the other way. I haven't found a way of doing it the other way whereby I can write something, and then to do that when I've tried to do that on the occasions I've tried to do that, passing it through these these machines. It's just extracted so much of what I wanted to say.

429

00:59:21.389 --> 00:59:29.490

Participant 11: That I've not that I've I've found it. I can't do it in that in that way it's only for me. It's only unidirectional. I can do it.

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00:59:29.490 --> 00:59:29.980

Karen Gainey: Yeah.

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00:59:29.980 --> 00:59:31.719

Participant 11: Does that make sense? Yeah, it makes sense. Yeah.

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00:59:31.720 --> 00:59:32.849

Karen Gainey: Of course. Yep.

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00:59:32.850 --> 00:59:33.290

Participant 11: Bye.

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00:59:33.290 --> 00:59:40.610

Karen Gainey: That's very similar to what I've heard from other other people, you know, that makes complete sense.

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00:59:40.610 --> 00:59:41.170

Participant 11: One.

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00:59:41.690 --> 00:59:50.640

Karen Gainey: I guess. Finally, where do you see? Or where would you like to see the future of these sort of summaries?

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00:59:50.950 --> 01:00:13.350

Participant 11: Right? Okay, well, I'd like to be. I'd like to be. I would like it to be a mandatory part of a board discussion, just like in commercial boards. You know, we have to discuss the finances at some stage in the meeting. If it's quarterly meeting. I think you know this, this should be something that is, that remains on the object on the agenda unless or until it shouldn't be on the agenda.

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01:00:13.350 --> 01:00:27.359

Participant 11: So, as I say, these kind of deep scientific journals, maybe that's inappropriate. I think the volume of people of regular people, if you like, who would seek that information is very small.

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01:00:27.370 --> 01:00:43.740

Participant 11: but for other general journals I think it should be something that should be reviewed on an annual basis if they're not doing it, and probably on a biannual basis, if they're doing it just to check in to see that they're doing it as optimally as they could.

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01:00:44.149 --> 01:01:01.780

Participant 11: Because let's not forget that even those who are doing it. At the moment they're they're not doing it optimally, as we've discussed earlier. Likely because many many of that group, you know plain language summaries. That's a big bag of people who all have individual needs. So

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01:01:02.500 --> 01:01:02.840

Karen Gainey: First.st

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01:01:03.340 --> 01:01:07.390

Participant 11: Yeah. So so that would be. That would be my main, my main

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01:01:07.480 --> 01:01:20.509

Participant 11: desire, if you like to see this topic treated more seriously to the extent that it becomes part of a. There was a very good book you were talking about that Danny and Kruger. So there are 2 books I love.

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01:01:20.510 --> 01:01:40.150

Participant 11: It's not complicated. Okay? So if you haven't read that, I really strongly recommend any person I meet these days, I recommend that they read that book. It's not complicated. What that does is that that discusses the distinction between complicated and complex. And these are 2 things, 2 concepts

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01:01:40.150 --> 01:01:48.090

Participant 11: that are confused. There's a huge difference between complicated and complex, and I think it's imperative to understand

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01:01:48.270 --> 01:02:02.848

Participant 11: the distinction between those 2 in order to understand almost anything in life and and this this topic, I think, requires an understanding of the distinction between those 2 concepts. The

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01:02:03.670 --> 01:02:06.580

Participant 11: okay, that's the did. I say I was going to mention 2 books.

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01:02:06.740 --> 01:02:12.010

Participant 11: So I've already forgotten the other one. Okay, so so the other one is presumably less in less important.

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01:02:12.450 --> 01:02:13.000

Karen Gainey: So, if you.

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01:02:13.000 --> 01:02:14.706

Participant 11: You were talking about

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01:02:15.560 --> 01:02:16.380

Karen Gainey: Dunning, Kruger.

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01:02:16.380 --> 01:02:38.099

Participant 11: Dunny and Kruger the importance of language summaries putting them on the agenda. every year. Yeah, I think I think that's I think that's pretty much. I think that's pretty pretty much it. I think that the I think that it, you know this. It needs to be on the agenda needs to be mandatory.

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01:02:38.940 --> 01:02:41.340

Participant 11: That's that's what I would do if I was.

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01:02:42.576 --> 01:02:43.390

Karen Gainey: The case.

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01:03:57.660 --> 01:04:00.709

Participant 11: Look at New Zealand. New Zealand does, of course. So

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01:04:01.710 --> 01:04:09.710

Participant 11: I mean, New Zealand is the only other country besides America that allows some pharmaceutical advertising on on television, and so forth, direct to consumer.

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01:04:09.710 --> 01:04:10.210

Karen Gainey: That.

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01:04:10.210 --> 01:04:11.189

Participant 11: The essay.

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01:04:11.190 --> 01:04:11.850

Karen Gainey: That.

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01:04:11.850 --> 01:04:14.530

Participant 11: Yeah. So it's just right next door to you. Oh, yeah.

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01:04:14.530 --> 01:04:17.340

Karen Gainey: Yeah, yeah, no. I didn't know that.

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01:04:17.610 --> 01:04:17.980

Participant 11: We do?

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01:04:17.980 --> 01:04:19.160

Karen Gainey: Right, yeah.

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01:04:19.160 --> 01:04:20.719

Participant 11: Yes. Quite right. Yeah. Yeah.

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01:04:20.720 --> 01:04:21.100

Karen Gainey: Yeah.

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01:04:21.100 --> 01:04:29.400

Participant 11: That's not say the medicines are a bad thing. Of course they're not. But the but the pharmaceutical lobby is a is a is a bad thing.

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01:04:29.400 --> 01:04:30.780

Karen Gainey: Very powerful. One. Yeah.

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01:04:30.780 --> 01:04:31.650

Participant 11: Yeah.

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01:04:31.950 --> 01:04:39.940

Karen Gainey: Oh, well, thank you so much, I've thoroughly enjoyed talking to you. I knew it would be interesting. And

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01:04:40.460 --> 01:04:47.379

Karen Gainey: what you put in Cochrane Exchange really drew me in. Obviously thought you'd be wealth of information. And you

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01:04:48.100 --> 01:04:51.609

Karen Gainey: I really appreciate your time, and for reaching out.

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01:04:51.610 --> 01:05:03.190

Participant 11: No, not at all. It works both ways, Karen. You know I thoroughly enjoyed our conversation. I wish you obviously all the very best with your with your research, and thank you for accepting and having this conversation grateful for your time as well. Thank you.

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01:05:03.190 --> 01:05:07.750

Participant 11: Thank you so much. And would you like to see the Transcript?

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01:05:07.750 --> 01:05:09.059

Participant 11: I don't need to see that.

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01:05:09.060 --> 01:05:09.439

Karen Gainey: Is that okay?

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01:05:09.930 --> 01:05:10.260

Participant 11: All right.

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01:05:10.260 --> 01:05:10.880

Participant 11: Yeah. Okay.

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01:05:10.880 --> 01:05:12.190

Karen Gainey: Trouble at all. All right.

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01:05:12.190 --> 01:05:12.620

Participant 11: Okay.

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01:05:12.620 --> 01:05:14.419

Karen Gainey: Think of that second book. Just pop me in.

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01:05:14.420 --> 01:05:15.760

Participant 11: I will, too. I will, too. Yeah.

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01:05:16.125 --> 01:05:16.490

Karen Gainey: Right.

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01:05:18.262 --> 01:05:22.460

Karen Gainey: I will look that up. It's it rings a bell. I will look.

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01:05:22.460 --> 01:05:24.590

Participant 11: Yeah. Yeah. Good. Good. Good. Okay.

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01:05:24.590 --> 01:05:26.340

Karen Gainey: Alright! Have a great rest of the day.

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01:05:26.340 --> 01:05:29.430

Participant 11: Thank you. Have a great day all the best. Bye, for now bye, for now.