WEBVTT

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00:04:04.030 --> 00:04:07.949

Participant 2: Hi, Karen, how are you?

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00:04:08.450 --> 00:04:10.140

Karen Gainey: Good! How are you?

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00:04:10.140 --> 00:04:11.570

Participant 2: Very good happy New Year.

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00:04:12.090 --> 00:04:13.370

Karen Gainey: You too.

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00:04:13.370 --> 00:04:14.350

Participant 2: Thank you.

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00:04:15.170 --> 00:04:16.600

Karen Gainey: Nice to meet you.

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00:04:16.620 --> 00:04:18.950

Participant 2: Nice to meet you all good.

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00:04:18.950 --> 00:04:19.550

Karen Gainey: Thank you.

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00:04:21.880 --> 00:04:26.829

Karen Gainey: Thank you for agreeing to do this. I really appreciate it, especially so early in the New Year.

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00:04:27.966 --> 00:04:34.369

Participant 2: That's still, the week where we don't have a lot of things ongoing. So both of the people on vacation. So that's a

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00:04:34.540 --> 00:04:37.219

Participant 2: the sweet spot to do such stuff.

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00:04:37.920 --> 00:04:42.319

Karen Gainey: Yeah. Okay. Oh, that's great. Are you back at work officially?

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00:04:42.625 --> 00:04:44.459

Participant 2: Am. Yeah. Yeah. Came back yesterday.

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00:04:44.900 --> 00:04:51.504

Karen Gainey: Okay, okay, all right. Well, that's great. Thank you so much. Again.

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00:04:52.934 --> 00:05:07.070

Karen Gainey: yeah. Just I know it's it's been a little while since we're emailing. And I sent you information I just wanted quickly, before we start, just double check. If you had any questions or anything before we we start, since.

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00:05:07.610 --> 00:05:08.690

Participant 2: No, I

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00:05:08.840 --> 00:05:21.729

Participant 2: if you can just give me like a short outlook on the aims of this, and what the idea behind is, and what you're going to do with the data just for curiosity. I mean, I think it's an interesting, especially like if you're in the publishing business. So.

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00:05:23.020 --> 00:05:39.859

Karen Gainey: For sure. Yeah, I just want to go through a couple of things while I think of it. To as a reminder. I'm auto audio recording this so I can transcribe it. And I've got zoom transcript so

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00:05:41.260 --> 00:05:48.294

Karen Gainey: as a as a function going as well. But I'm not going to keep any chat or any video of this.

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00:05:48.930 --> 00:05:59.545

Karen Gainey: so the purpose of this, this is the final study. In my Phd, oh, and please let me know if I'm speaking too quickly.

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00:05:59.970 --> 00:06:00.680

Participant 2: All good! Go ahead!

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00:06:20.660 --> 00:06:42.989

Karen Gainey: all my studies have been on the use of plain language summaries as a tool for communicating health research to a general audience. So I started with a scoping review which looked at the guidelines for plain language, summaries in health journals, and then did a comparison between the guidelines and plain language summaries.

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00:06:42.990 --> 00:06:58.920

Karen Gainey: then those have been published. Then I've recently submitted a study where I asked consumers of plain language summaries what they thought the ideal plain language summary should look like

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00:06:59.120 --> 00:07:17.489

Karen Gainey: based on that. And that was a qualitative series of semi-structured interviews. I've put together some questions to kind of bring everything together. So we know what's out there, what readers would really like. So I'd really like to get an understanding from the journal end of what's practical

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00:07:17.690 --> 00:07:34.859

Karen Gainey: and what's possible. So really, what I want to understand is what are the decisions and factors that go into publishing plain language summaries and their guidelines that authors need to to follow.

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00:07:35.360 --> 00:07:40.050

Karen Gainey: And so really, what are the considerations? Any barriers.

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00:07:40.200 --> 00:07:47.490

Karen Gainey: anything new that's in the field that that is. So we'll talk about

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00:07:47.820 --> 00:07:57.930

Karen Gainey: some new areas and really just experiences and perspectives and thoughts. So we can bring everything together in a.

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00:07:58.440 --> 00:08:01.839

Karen Gainey: you know, complete the the circle. If that makes sense.

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00:08:02.750 --> 00:08:03.939

Participant 2: Makes a lot of sense. Yeah.

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00:08:04.240 --> 00:08:23.030

Karen Gainey: Great, all right. So I guess I'm thinking of your experiences. So your experience can be either with your current journal or experiences from elsewhere. So it's all useful. And

I really don't want you to hold back. And just tell me positives. I really want to know the reality.

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00:08:23.710 --> 00:08:30.380

Karen Gainey: And if it's that plain language. Summaries are not a big priority. That's important.

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00:08:31.199 --> 00:08:35.039

Karen Gainey: So I'm just trying to understand the real picture out there.

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00:08:35.390 --> 00:08:36.390

Karen Gainey: So

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00:08:38.490 --> 00:08:47.080

Karen Gainey: before I start, I just had a couple of demographic questions that I'm now putting on a qualtrics link. But I developed that after.

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00:08:47.400 --> 00:08:52.370

Participant 2: Yeah, I I just like, if that is the link you sent me. I was just like filling it out like 10 min ago. If ever there is.

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00:08:52.370 --> 00:08:53.850

Karen Gainey: Oh, all right, we'll leave that.

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00:08:53.850 --> 00:08:56.229

Karen Gainey: That'll save some time. Appreciate it.

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00:08:56.230 --> 00:08:59.240

Karen Gainey: Appreciate that fantastic, all right.

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00:08:59.860 --> 00:09:09.191

Karen Gainey: So I've got a couple of I've got a few different kind of subject areas to cover. So I wanted to just start off

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00:09:09.940 --> 00:09:19.340

Karen Gainey: really, just understanding how decisions are made. At the journals. So I guess if we can just start just telling me a little bit about your role.

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00:09:20.170 --> 00:09:20.730

Participant 2: Yep.

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00:09:21.410 --> 00:09:22.960

Karen Gainey: That would that would help.

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00:09:23.663 --> 00:09:30.069

Participant 2: Indeed I good question. I had the impression, like all journals, are functioning the same way.

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00:09:31.040 --> 00:09:35.629

Participant 2: That actually the editor in chief. That's my role at the European Urology Open Science. One of the.

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00:09:35.630 --> 00:09:36.070

Karen Gainey: Yep.

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00:09:36.070 --> 00:09:48.320

Participant 2: Main European journals with regards of urology like the family. Let's say you have European urology, like the mother journal, which is probably the highest ranked surgical Journal. We have currently or.

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00:09:48.650 --> 00:10:01.229

Participant 2: Surgical specialties taken together, and there are 3 sister journals which is European urology, oncology, European urology focus, and European urology, open science, and I'm responsible for open science.

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00:10:01.230 --> 00:10:23.130

Participant 2: and probably aware of the needs that all journal families would need to have this open access option. And that's what I'm covering. And the 4 of us. We have all the same functioning. We grew up together, or let's say, the mother journal started, and then the sister journals were created and started. And we just copy paste, the functioning so.

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00:10:23.130 --> 00:10:23.860

Karen Gainey: Gotcha.

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00:10:23.860 --> 00:10:48.929

Participant 2: As editor in chief, I would receive 1st all upfront submissions to European neurology. Open science would check if that would make sense to be evaluated. If that is the case, then I would send it to the associate editors. They would take care of all the reviews, and to gathering the reviews, having a look at the reviews, and then, let's say, synthesizing what comes from the reviews, and then having their decision provided.

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00:10:49.270 --> 00:10:56.819

Participant 2: they send it back to me, and I have then a look and decide myself. If that is finally, then reject a revision or an accept.

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00:10:57.190 --> 00:11:01.789

Participant 2: and then it goes back to the, to the to the author.

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00:11:02.672 --> 00:11:14.139

Participant 2: And I also get transfers from the other journals, so from the sister journals. So if they think we are, let's like the the lower tier journal being open access.

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00:11:14.532 --> 00:11:43.620

Participant 2: So we would receive, let's say, transfers from all 3 other sister journals, or the mother journal, and I would then be invited by the editor in chief for an article they would

not consider for their journal to be accepted, but they, where they think the article is good enough, or should be inside of the Journal family, and then they offer me to have a look at it, and if I think that's of acceptable value. Then I would offer the transfer

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00:11:43.790 --> 00:11:59.219

Participant 2: acceptance, not guaranteed, but we would evaluate, then this article under the roof of open science, and then the same process, and if I think no, I'm not interested, or it would be like copying what we have already accepted or published a few weeks or a few months ago.

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00:11:59.620 --> 00:12:02.290

Participant 2: not going to the strategy, then I would also reject it.

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00:12:02.560 --> 00:12:05.309

Participant 2: And then there are obviously also submissions

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00:12:05.470 --> 00:12:25.320

Participant 2: that we straight reject just because this subject is not appropriate to our journal, because the quality is so low, or we just had a publication on the same topic, and we don't want to repeat something we published already recently. That's how we work. And then there are other journals, obviously, where the editor in chief

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00:12:25.750 --> 00:12:30.869

Participant 2: is less active. Let's say where all the work is done by the associate editors

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00:12:31.000 --> 00:12:43.570

Participant 2: that seem to have a function as an editor in chief, because they finally decide if an article is accepted or not, and they would then send the articles for a variation to the how they call it the

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00:12:43.850 --> 00:12:49.040

Participant 2: associate editor, assistants, or whatever they have, like a 3rd

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00:12:49.520 --> 00:12:58.890

Participant 2: level inside of the journal organization. And I just recently learned that actually, inside of these systems, the editor in chief does not have a

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00:12:59.470 --> 00:13:05.269

Participant 2: a real active role, was surprised to hear that. But yeah, there are different ways, obviously, to organize

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00:13:05.480 --> 00:13:07.679

Participant 2: journals and and how to run things.

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00:13:08.190 --> 00:13:09.099

Participant 2: But we are

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00:13:09.550 --> 00:13:17.069

Participant 2: probably inside of the journal X family. The editing chief actually receives everything up front and decides finally everything.

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00:13:17.590 --> 00:13:22.810

Participant 2: and bases the decisions obviously heavily on the revenues, and the associate editors.

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00:13:23.620 --> 00:13:53.039

Karen Gainey: Yeah, that's really helpful. Because what I'm trying to understand is the relationship between the journal and the publisher. And where decisions are made. So it sounds like within your. So I know your publisher is Lsev. So what's the relationship like with your group of Urology journals and Lcvia? And where are the decisions made and what we're.

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00:13:53.370 --> 00:13:58.970

Karen Gainey: I guess what level of autonomy or.

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00:13:59.760 --> 00:14:03.020

Participant 2: I would say I might be wrong, because.

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00:14:03.180 --> 00:14:13.109

Participant 2: running only the Open Science Journal, I might have less involvement with Elsevier. I do not feel any influence from Elsevier at all on on what we decide and what we do.

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00:14:14.040 --> 00:14:31.099

Participant 2: We just follow our aim of note, also that the let's say, journal activity and revenues are shared between the EU, the European Association of Urology and Elsevier. So Elsevier is not the only, let's say.

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00:14:31.400 --> 00:14:42.690

Participant 2: stakeholder here, but obviously also the scientific association. But we have a complete, let's say, wide sheet of doing whatever we would like to do.

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00:14:42.940 --> 00:14:54.527

Participant 2: and there are no obligations. There are suggestions coming in from Elsevier. It's rather us asking Elsevier. To help us to go forward, but I would rather consider them being service providers.

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00:14:55.030 --> 00:14:57.360

Participant 2: allowing us to have a journal running

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00:14:57.730 --> 00:15:08.790

Participant 2: and giving us the infrastructure. But there's not at all any input from Elsevier to decide or to accept or to increase or to lower whatever comes.

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00:15:09.550 --> 00:15:18.360

Karen Gainey: Right? Okay, that's good for me to understand that. How that that works so that that kind of relationship?

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00:15:20.340 --> 00:15:31.930

Karen Gainey: so can you tell me a bit about now your experience with plain language summaries, or I know for your journal they're called patient Summaries. Yeah, specifically with that sort of summary.

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00:15:31.930 --> 00:15:37.469

Participant 2: So. So we all copy paste the same format from for all 4 journals, so.

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00:15:38.120 --> 00:15:59.310

Participant 2: journal X and Mother Journal usually sets the stage so what they would like to have. We use it then for us. Obviously the before editors. In chief we find a consensus would not probably do something in one journal which is completely unacceptable for another editor-in-chief, and we are all knowing each other. So it's unlikely to happen that there is a complete contradiction.

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00:15:59.370 --> 00:16:08.550

Participant 2: But usually we do what the mother journal is doing, especially because we want to have it like easy to understand, and having, like a recognizable pattern.

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00:16:08.680 --> 00:16:29.910

Participant 2: and the patient summary is part of what we provide usually with the abstract. So we have the abstract giving the scientific summary and message, and then below, we

have, like the patient summary, which is very short. Let's say I think it's might be 4 or 5 lines, one or 20 words or so a bit more, maybe.

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00:16:30.760 --> 00:16:32.359

Participant 2: and that is usually

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00:16:32.870 --> 00:16:46.449

Participant 2: targeting the non urologist or the non-physician to provide to the message of the of the article. I'm not really sure that such a short message is really of a lot of help.

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00:16:46.870 --> 00:17:06.930

Participant 2: but obviously it is something that is important that we are able not only to target a scientific audience and readership, but also like a more broader one, might even be more important. And also, let's say, targeting, not only neurological readership, but also

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00:17:07.180 --> 00:17:14.679

Participant 2: more general physicians. Readership. There are some journals that really target a very broad

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00:17:14.950 --> 00:17:26.020

Participant 2: audience. Physicians, audience that seem to be very successful, and really keeping the scientific language as low as possible, to make sure that

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00:17:26.490 --> 00:17:29.959

Participant 2: all are served, and everybody understands what is written in there.

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00:17:30.900 --> 00:17:40.809

Participant 2: That's 1 point. The more important point is actually that those who prepare the manuscript. The authors

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00:17:41.080 --> 00:17:44.600

Participant 2: not necessarily understand what is meant with the patient summary.

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00:17:45.420 --> 00:17:55.369

Participant 2: So we very often just get a copy paste from the conclusions of the abstract, which obviously is not the aim behind it. And I think there's a clear

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00:17:56.340 --> 00:17:57.420

Participant 2: problem

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00:17:57.550 --> 00:18:08.729

Participant 2: with the understanding of a scientist of what might be plain language and how that should be made, and how that should be provided, and how that could be developed.

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00:18:09.775 --> 00:18:10.870

Karen Gainey: That's so interesting.

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00:18:10.870 --> 00:18:17.419

Participant 2: Guidance and tell them. But I don't think for scientists it's very clear what plain language would be.

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00:18:18.291 --> 00:18:27.429

Participant 2: And I wrote some articles for patient associations, and sometimes for you, even going

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00:18:27.540 --> 00:18:31.220

Participant 2: out of your scientific terms. You think that is

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00:18:31.430 --> 00:18:37.569

Participant 2: obviously something that is an appropriate term, and it could be completely not appropriate.

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00:18:38.050 --> 00:18:41.359

Karen Gainey: What probably would be very helpful is to have somebody.

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00:18:41.850 --> 00:18:49.260

Participant 2: Cross, checking this part like a patient, make sure that this is understandable. Because without this

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00:18:49.640 --> 00:18:54.050

Participant 2: many would probably not be plain language.

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00:18:55.510 --> 00:19:06.080

Karen Gainey: Yeah, yeah, that's is that something you think the mother journal or your group of editors might do in the future? Or is, it's obviously.

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00:19:06.080 --> 00:19:09.529

Participant 2: Probably that is something. If we would like to spread our

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00:19:10.550 --> 00:19:18.810

Participant 2: journals to this sort of audience, probably would need to invest into it, but then probably would need to have also

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00:19:18.970 --> 00:19:22.789

Participant 2: more information. So we would probably need to have, like an abstract, sized.

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00:19:22.890 --> 00:19:28.570

Participant 2: patient, plain language summary of the paper to make sure that

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00:19:28.790 --> 00:19:33.249

Participant 2: there's more getting information getting across than just like the

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00:19:33.390 --> 00:19:39.869

Participant 2: the 4 or 5 lines. Other question is, would they really need it? Because, on the other hand.

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00:19:40.230 --> 00:19:49.039

Participant 2: the non-scientists might not need all the details behind it, just like the conclusion, on the other hand, that probably then appropriate to have the patient summary.

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00:19:49.350 --> 00:19:50.090

Karen Gainey: Hmm.

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00:19:50.090 --> 00:19:55.618

Participant 2: Probably there's a not like like the ideal one solution for it. You would need to think about what

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00:19:57.090 --> 00:20:04.050

Participant 2: the best compromise would be, and and probably would make more sense to have somebody summarizing this

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00:20:05.000 --> 00:20:11.059

Participant 2: not being the author, but somebody really familiar with that plain language summary. You make sure that

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00:20:12.190 --> 00:20:18.679

Participant 2: language is the right one, and the content is understandable for somebody who's not in the in the field.

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00:20:19.710 --> 00:20:24.460

Karen Gainey: Yeah. And and that's and I'm speaking to other people. That's

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00:20:25.117 --> 00:20:32.380

Karen Gainey: one of the concerns they raised was the potential for that extra step to delay the publication

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00:20:32.950 --> 00:20:49.770

Karen Gainey: of the entire manuscript, and weighing up. Was that worth it for the sake of what really amounts to half the size of an abstract, and there was no clear answer to that. But that was kind of part of the

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00:20:50.010 --> 00:20:52.860

Karen Gainey: the challenge, the conundrum.

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00:20:52.860 --> 00:20:54.670

Participant 2: Yeah, and

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00:20:54.820 --> 00:21:08.919

Participant 2: maybe more important than like, the methods probably would be the clinical context. And if that is something we added now to our format as well, that we have an an paragraph that puts that into the clinical context.

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00:21:09.290 --> 00:21:20.230

Participant 2: and also like a comment, then from the associate editor to like a very brief editorial, to summarize strength and weaknesses.

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00:21:20.410 --> 00:21:32.639

Participant 2: which might also go in the same direction, not necessarily in plain language, but giving a little bit the perspective on why this article is important, and where that article fits into the current literature.

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00:21:33.080 --> 00:21:44.169

Karen Gainey: Yes, yeah. I remember seeing that I noticed I was just wondering, thinking of the audience, if you know the decision.

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00:21:44.170 --> 00:22:06.750

Karen Gainey: because I know from my scoping review. There's a lot of different terms or labels used for this sort of summary, wondering if you have any sense of why your group of journals chose the label Patient summary, and if that was quite deliberate, to try and speak to a very specific target audience.

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00:22:11.730 --> 00:22:18.089

Participant 2: I I think that's in all specialities. We have a strong trend, and probably need

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00:22:18.250 --> 00:22:25.890

Participant 2: to get patients involved. If that is for scientific meetings for guidelines.

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00:22:26.080 --> 00:22:31.850

Participant 2: for whatever we do inside of a scientific society. And

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00:22:32.040 --> 00:22:37.610

Participant 2: part of this is also like the publications, to make sure that patients get the message.

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00:22:38.020 --> 00:22:49.110

Participant 2: or or like a part of the the target. And that's why we intentionally, indeed, selected the term patient summary, because it really targets the patient

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00:22:49.500 --> 00:22:56.399

Participant 2: might be concerned with the publication, the content of the publication, and to make sure that they understand that this part

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00:22:56.820 --> 00:22:59.950

Participant 2: is for them, and that they might get

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00:23:00.210 --> 00:23:06.060

Participant 2: some plain language information. We thought this would be the most appropriate term for it.

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00:23:06.570 --> 00:23:12.949

Participant 2: What would be alternatives from other journals? What did they call it? Like just plain language, summary or.

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00:23:12.950 --> 00:23:18.837

Karen Gainey: Yeah. Plain language summary is pretty common. Lay summary with some of them.

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00:23:19.920 --> 00:23:27.120

Karen Gainey: what are some of the others? This is what I'm trying to to drill down into, because

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00:23:27.500 --> 00:23:51.509

Karen Gainey: there's a real kind of seems to be possibly a disconnect or confusion or disharmony between the labels and the audience, and I'm trying to find out where the decisions lie, because some journals, particularly some elsevia journals, call this kind of summary key points or key messages. But the target audience, as you alluded to before, is quite broad.

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00:23:51.800 --> 00:24:14.840

Karen Gainey: includes clinicians, researchers, or non specialist researchers and the general public or consumers. So I'm trying to find out how deliberate some of these labels are in, and if there's any connection to the target audience, or if it's just meant to be a catchy term.

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00:24:15.710 --> 00:24:22.639

Participant 2: That's it. I mean, you probably be being a native speaker might have

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00:24:22.980 --> 00:24:27.510

Participant 2: a different perspective on it, but I would say that, still

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00:24:29.010 --> 00:24:38.290

Participant 2: difficult to judge, but at least Western world, 70 80% of the patients

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00:24:38.480 --> 00:24:44.659

Participant 2: would not necessarily be very familiar with English as a language.

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00:24:45.070 --> 00:24:47.759

Participant 2: and for me, like plain language.

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00:24:48.110 --> 00:24:51.850

Participant 2: being not inside of the scientific world, and publishing

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00:24:52.150 --> 00:24:55.659

Participant 2: as a non-native speaker, I would not know what it is.

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00:24:57.920 --> 00:25:02.599

Participant 2: This is targeting me plain language for me. What you know I mean, what is it? I have no idea.

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00:25:03.230 --> 00:25:09.519

Participant 2: Lay language, neither lays would not, would not necessarily be a word that I would have recognized

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00:25:10.270 --> 00:25:13.140

Participant 2: being not too much into English.

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00:25:13.668 --> 00:25:16.449

Participant 2: Being the term for late. So that's why pay.

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00:25:16.800 --> 00:25:23.890

Participant 2: Think that is easy to understand. Patient is probably with the European language, is something that is

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00:25:24.040 --> 00:25:34.299

Participant 2: understandable for all languages. So you would quickly pick up that this is for you, and what you might, as you said, made a general population or general audience

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00:25:34.910 --> 00:25:41.069

Participant 2: summary, that that might be also a term, and easier to understand, for those who are not native speakers.

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00:25:41.170 --> 00:25:42.010

Participant 2: but.

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00:25:42.574 --> 00:25:48.790

Karen Gainey: And lay language. I would not be sure that this would be something easily recognized.

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00:25:49.420 --> 00:25:58.040

Participant 2: By those who are supposed to read it and to recognize it as their part of information.

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00:25:58.240 --> 00:25:59.720

Participant 2: The target spent.

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00:26:00.230 --> 00:26:09.730

Karen Gainey: That's thank you for sharing that. See, this is what I need to hear, things that I wouldn't know, and things that

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00:26:09.890 --> 00:26:14.930

Karen Gainey: are not kind of obvious

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00:26:15.050 --> 00:26:23.850

Karen Gainey: to me. This is great because one of the things that consumers. So I spoke to consumers across the world.

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00:26:24.210 --> 00:26:40.939

Karen Gainey: across Europe, Uk, America, and Australia and one Asian country, and one of the themes was, we talked about labels, and one of the things they said was a lot didn't like the term patient, because they felt it was

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00:26:42.060 --> 00:26:49.330

Karen Gainey: talking down to them, and they didn't like to be labeled as a patient, and it wasn't very empowering.

168

00:26:50.220 --> 00:27:00.440

Karen Gainey: So it's but some didn't mind it. So it's it's so interesting to hear that. So it seems very contextual.

169

00:27:00.810 --> 00:27:06.440

Participant 2: Yeah. And then we're who said that these were, let's say.

170

00:27:07.030 --> 00:27:10.010

Participant 2: those who run the journal of the authors of these were patients.

171

00:27:10.010 --> 00:27:11.640

Karen Gainey: The patients. People who read.

172

00:27:11.640 --> 00:27:12.560

Participant 2: Yeah. Then, okay.

173

00:27:12.710 --> 00:27:13.430

Karen Gainey: Yeah. That's me.

174

00:27:13.430 --> 00:27:14.120

Participant 2: Surprising.

175

00:27:14.510 --> 00:27:16.181

Karen Gainey: Yeah, I mean that that is

176

00:27:17.340 --> 00:27:19.279

Karen Gainey: But now I'm wondering. 3 stage.

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00:27:19.280 --> 00:27:21.300

Participant 2: Direction we have, yeah.

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00:27:21.300 --> 00:27:29.129

Karen Gainey: Broke it down, whether they were European or whether they were non-european. That would be interesting. Now you've said that.

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00:27:30.290 --> 00:27:35.139

Participant 2: Yeah, I mean, I I never had the feeling like having the term patient in. There would be

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00:27:36.250 --> 00:27:38.980

Participant 2: looking down on them. I mean the

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00:27:39.230 --> 00:27:45.580

Participant 2: we have a relation with patients that is straightforward, everybody understands, and that you can

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00:27:46.320 --> 00:27:52.619

Participant 2: manage in a certain way, and and we are working on it and getting more into a patient centered management where the patient

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00:27:52.620 --> 00:27:53.050

Participant 2: you shouldn't

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00:27:53.050 --> 00:28:04.360

Participant 2: is participating in the decision making. Part of this is also providing scientific information to the patients so they can gather the information on their side, independent fashion.

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00:28:04.500 --> 00:28:07.899

Participant 2: But I never had the feeling like getting or addressing them

186

00:28:08.340 --> 00:28:10.259

Participant 2: with the term patient would be

187

00:28:11.290 --> 00:28:14.509

Participant 2: generate this sort of feeling. But it's a.

188

00:28:14.510 --> 00:28:16.169

Karen Gainey: Yeah. It wasn't across the board.

189

00:28:16.170 --> 00:28:16.760

Participant 2: Yeah, yeah.

190

00:28:16.760 --> 00:28:20.540

Karen Gainey: It was just a few people. So it was.

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00:28:21.130 --> 00:28:24.509

Karen Gainey: yeah, it may well have been non-european sentiment.

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00:28:24.690 --> 00:28:28.589

Karen Gainey: Yeah, that's interesting. But it's good to know.

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00:28:28.980 --> 00:28:36.140

Participant 2: But I think an important point is indeed like the perception you could get from a certain term. If you're not a native speaker.

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00:28:36.540 --> 00:28:37.960

Karen Gainey: Yeah, that's really important.

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00:28:37.960 --> 00:28:45.640

Participant 2: And we like a European association. What we are. We very often recognize that the native speakers obviously are

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00:28:46.130 --> 00:28:48.970

Participant 2: from a rhetoric position excellent.

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00:28:49.200 --> 00:29:10.540

Participant 2: but the content is not necessarily the easiest to understand, because they make jokes. Non native speaker would not understand, and as you were starting with, sometimes they are so quick and fluent that you have difficulties to follow, because it's just going too quick. And as a European association we are very much aware of these

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00:29:10.860 --> 00:29:17.100

Participant 2: issues you might have between native speakers and non native speakers. And, let's say, in Europe.

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00:29:17.360 --> 00:29:20.110

Participant 2: probably more than 90% are non-native speakers.

200

00:29:20.470 --> 00:29:33.300

Karen Gainey: Yeah, yeah. Well, I just mentioned it, because one thing that did come out was that the label was very important, and a poor label or a non descriptive label would turn them off reading further.

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00:29:33.480 --> 00:29:36.060

Karen Gainey: So that's why it

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00:29:36.860 --> 00:29:44.350

Karen Gainey: an important point. Yeah, not that anything's right or wrong. Just it was important to them. So

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00:29:44.730 --> 00:29:45.949

Karen Gainey: yeah, it's

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00:29:46.750 --> 00:30:01.648

Karen Gainey: that was that's really, really valuable. Just thinking about you you were talking before about when when I try and understand the submission process? So I know for your journal.

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00:30:02.770 --> 00:30:09.220

Karen Gainey: that oh, actually, can I just confirm? Are the patient summaries mandatory.

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00:30:09.750 --> 00:30:10.500

Participant 2: They are. Yeah.

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00:30:10.500 --> 00:30:11.330

Karen Gainey: Yeah, yeah, yeah.

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00:30:11.330 --> 00:30:11.730

Participant 2: Yep.

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00:30:11.730 --> 00:30:27.529

Karen Gainey: So when there's a new manuscript submitted online, do you require the patient summary to be submitted with the main document? Or is that as a separate

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00:30:27.820 --> 00:30:31.590

Karen Gainey: file or a supplementary like, with.

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00:30:31.590 --> 00:30:32.249

Participant 2: Is it with the.

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00:30:32.250 --> 00:30:33.190

Karen Gainey: Abstract.

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00:30:33.190 --> 00:30:38.260

Participant 2: Usually it is getting.

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00:30:42.560 --> 00:30:43.880

Karen Gainey: If you know.

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00:30:44.470 --> 00:30:52.600

Participant 2: There. I cannot tell you right now how that is. Just check.

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00:30:53.600 --> 00:30:57.299

Karen Gainey: That's okay. Cause I'm just. I'm just wondering about.

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00:30:57.300 --> 00:31:07.159

Participant 2: We have actually a journal manager that checks all submissions, and they would see if the patient summary is in there. They would send it back if it's not there. But

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00:31:07.160 --> 00:31:07.550

Participant 2: oh.

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00:31:07.550 --> 00:31:19.589

Participant 2: no! If we have like a grid where you need to fill it in like the abstract and and the the keywords and all that, and if you don't fill that in, then you would not be able to submit the entire manuscript. I cannot tell you how that is

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00:31:20.090 --> 00:31:22.430

Participant 2: If we have a separate box for patient

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00:31:22.550 --> 00:31:25.099

Participant 2: for summary. I think so, but I'm not sure.

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00:31:25.640 --> 00:31:26.410

Karen Gainey: Sure. Yeah. Like, if.

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00:31:26.410 --> 00:31:28.610

Participant 2: But anyhow, it is checked upon a submission.

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00:31:28.610 --> 00:31:29.020

Karen Gainey: Like.

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00:31:29.020 --> 00:31:33.450

Participant 2: And would be sent back to the author if the patient summary is not provided. Upfront.

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00:31:33.920 --> 00:31:44.789

Karen Gainey: Right cause it cause it's mandatory. Yeah, okay, do you have any idea how many people don't? Don't submit it and and have to. You have to chase up.

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00:31:44.790 --> 00:31:48.440

Participant 2: I have no idea now, because I I only receive, like the fully.

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00:31:48.620 --> 00:31:49.760

Karen Gainey: The full. Yeah.

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00:31:50.280 --> 00:31:52.950

Participant 2: Like. It's complete manuscripts. I would not

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00:31:53.180 --> 00:32:02.869

Participant 2: get an idea how many are sent back. I could see it if I go back to the history of the in the editorial manager, but usually I do not check that, because does not change anything for me.

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00:32:03.580 --> 00:32:14.559

Karen Gainey: Sure? When so does that mean when the manuscript goes to peer review? Would the would the patient summary be peer reviewed also?

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00:32:14.880 --> 00:32:20.439

Participant 2: Indeed. Yeah, that's part of the manuscript that is sent out to the associate editors and then to the reviewers. Yeah.

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00:32:21.140 --> 00:32:25.920

Karen Gainey: Do reviewers tend to comment much on the patient? Summary.

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00:32:26.880 --> 00:32:31.699

Participant 2: There is something that is indeed not really well explored

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00:32:31.930 --> 00:32:38.210

Participant 2: or paid attention to. But I understand why? Because

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00:32:38.800 --> 00:32:46.559

Participant 2: the review process obviously is the key point of the entire process of of publishing a scientific article

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00:32:46.680 --> 00:32:50.059

Participant 2: without a peer review, a constructive peer review.

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00:32:50.380 --> 00:32:55.370

Participant 2: We cannot go anywhere, and the most important target or or

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00:32:55.490 --> 00:33:02.860

Participant 2: objective we have, for this is scientific content methods. And then, obviously, the the conclusions you draw from it.

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00:33:03.590 --> 00:33:10.329

Participant 2: And I completely understand that they would not spend too much energy on what the patient summary contains.

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00:33:10.800 --> 00:33:22.476

Participant 2: And that is yeah. Fine for me also, with regards of the resources we have and the benefits we might get out of these resources. So for me also, that is not a priority.

242

00:33:23.190 --> 00:33:37.100

Participant 2: I obviously check that. But I would not necessarily neither pay too much attention on what the content is, if that could not be improved. And if that indeed is plain language, or if that is still like too scientific to be called plain language.

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00:33:37.830 --> 00:33:38.409

Karen Gainey: Right? Okay.

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00:33:38.410 --> 00:33:44.440

Participant 2: Though all articles, because before they are published, copy edited.

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00:33:44.770 --> 00:33:51.509

Participant 2: and maybe the copy editor is paying more attention to it, and then readjusting the plain language part.

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00:33:51.860 --> 00:33:59.489

Participant 2: I would not know if that is the case, because I usually would not recheck the article once it's copy edited.

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00:34:00.540 --> 00:34:18.249

Karen Gainey: Yeah. Okay. So looking at your guidelines, which is a paragraph that says it should be 2 to 3 sentences, or however many, and written this way. Would it be the copy editor who might look to see if it complies.

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00:34:18.250 --> 00:34:25.411

Participant 2: That is possible. But yeah, usually the the work of the copy editor is quite extensive. So you receive sometimes the proof and

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00:34:25.920 --> 00:34:29.169

Participant 2: like it feels like every sentence did get a change.

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00:34:29.779 --> 00:34:37.020

Participant 2: So it's difficult to to really be sure that yeah, to to recognize if there are some parts that are more

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00:34:37.230 --> 00:34:38.239

Participant 2: changed.

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00:34:39.020 --> 00:34:43.510

Participant 2: Oh, yeah, edited than the others. So

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00:34:43.639 --> 00:34:45.370

Participant 2: I never really checked that part.

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00:34:46.000 --> 00:34:46.940

Participant 2: Yeah

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00:34:46.949 --> 00:34:54.849

Participant 2: point. We might have a look at this, if the copy editor might not have a closer look and and train the copy editor. That is not something to improve.

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00:34:55.670 --> 00:34:56.210

Karen Gainey: Hmm.

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00:34:58.359 --> 00:35:03.400

Participant 2: Taking advantage of the discussion I have with you for agenda, as well.

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00:35:03.832 --> 00:35:06.427

Karen Gainey: I've just given you more work.

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00:35:07.060 --> 00:35:08.825

Participant 2: No, they're good ideas. Why not?

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00:35:09.980 --> 00:35:14.501

Karen Gainey: That's good. Well, I'm just thinking about

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00:35:15.820 --> 00:35:32.640

Karen Gainey: actually, I meant to ask the decision to make this patient summaries mandatory. Was that a decision between all of you as a group? Or was that again the mother group? The mother journal, had established that.

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00:35:32.640 --> 00:35:37.609

Participant 2: I think we have that ongoing for probably 1015 years now.

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00:35:37.820 --> 00:35:41.350

Participant 2: And I started in 2019

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00:35:41.620 --> 00:36:06.080

Participant 2: for the open science. So that was already existing before I got involved. So I just took it over. But I have the impression that this was already existing when the mother journal was existing only in isolation, so that was already quite early established, and to make it once more recognizable, make sure that all articles to show a little bit, the same format, the same information.

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00:36:07.050 --> 00:36:11.685

Participant 2: All this here is the

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00:36:13.420 --> 00:36:15.589

Participant 2: like to take home messages and all that.

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00:36:15.740 --> 00:36:18.510

Participant 2: Try to have the same format for all articles.

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00:36:19.030 --> 00:36:19.910

Participant 2: Yeah, yeah.

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00:36:20.100 --> 00:36:21.020

Participant 2: An obligation.

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00:36:21.710 --> 00:36:32.680

Karen Gainey: Yeah, okay, so how does that work with the all of you editors? Is that does that make things easier? Having that same format, and things that consistent.

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00:36:32.680 --> 00:36:45.830

Participant 2: It makes it easier, first, st because we would like to have the brand of European neurology be recognized, and seeing an article, whatever of the sister or mother journal it comes from. People should recognize this is European neurology.

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00:36:46.230 --> 00:37:05.260

Participant 2: And then because we would also be open for transfers, it makes a lot of sense that once you have the format for a European urology article, it would fit into all 4 journals,

so you would not each time you have a transfer rework on the layout and reformat. The manuscript you just can

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00:37:05.260 --> 00:37:21.109

Participant 2: transfer if there are revisions to be done. If the transfer is often after a review, for example, then obviously we do the revisions. If that's just like a transfer before a formal review process, then you can just like submit as it is.

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00:37:22.110 --> 00:37:28.219

Participant 2: and we would like to have that process being as easy as possible to have a nice flow inside of the journals.

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00:37:28.810 --> 00:37:31.955

Karen Gainey: Yeah, of course, that makes sense.

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00:37:32.720 --> 00:37:50.876

Karen Gainey: So with the the guidelines for the patient summary. If, for example, one of one of yourself or one of the other editors in chief had an idea or wanted to. For example, if you wanted to

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00:37:51.580 --> 00:38:07.799

Karen Gainey: have a patient look at the patient summaries, or involve a different process. How would that come about implementing a new change or reviewing the guidelines? Has there been a recent review of them.

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00:38:07.800 --> 00:38:08.640

Participant 2: For the.

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00:38:08.640 --> 00:38:09.570

Karen Gainey: You know.

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00:38:10.132 --> 00:38:12.860

Participant 2: Like the the guidelines for the patient summary, you would

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00:38:13.130 --> 00:38:20.310

Participant 2: you mean? I don't think that was like checked by a patient.

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00:38:21.069 --> 00:38:35.840

Participant 2: We have our official guidelines that that are checked by patients before they are published. Obviously, and patients are involved in the guideline process like prostate cancer guidelines and and kidney cancer, and so on for the

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00:38:36.040 --> 00:38:41.909

Participant 2: author information. I don't think the patient didn't check it. I'm not really sure that that would be

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00:38:43.120 --> 00:38:44.149

Participant 2: lot of help.

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00:38:44.700 --> 00:38:57.580

Participant 2: because we don't need, let's say, patients to tell a scientist how to use plain language. I don't know who might be the best teacher for this, but I would not expect a patient being very helpful on that level.

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00:38:59.990 --> 00:39:09.370

Participant 2: What would be helpful indeed, like having a a patient or a lay rereading this part before publication.

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00:39:09.800 --> 00:39:10.500

Participant 2: But

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00:39:12.440 --> 00:39:19.029

Participant 2: then, I'm not really sure we would be able to find somebody who would provide that in a

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00:39:19.990 --> 00:39:21.520

Participant 2: fruitful fashion.

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00:39:22.000 --> 00:39:37.869

Participant 2: Because, yeah, either you're familiar with the scientific publication process, and then you're probably close to a scientist, and you might get already a lot of bias out of it, or you're not. And then you might probably slow down the entire publication process and and.

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00:39:39.150 --> 00:39:40.180

Karen Gainey: Yeah.

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00:39:40.290 --> 00:39:56.790

Karen Gainey: So I guess what I'm trying to understand is, if there was any changes to how the patient summaries were written, or the guidelines, or how they're processed? I guess, trying to understand. What would that? What would any change involve?

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00:39:58.430 --> 00:40:01.180

Karen Gainey: Given that you want to keep things consistent.

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00:40:03.167 --> 00:40:11.640

Participant 2: What we would do. We would indeed agree together, the 4 of us, if we do changes or not, but the problem would also be

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00:40:12.260 --> 00:40:28.199

Participant 2: the authors do have feels like 5 or 6 pages of authors, information how they should do things, and what they should respect, and what also is done in systematic fashion is a statistical review of our

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00:40:29.640 --> 00:40:31.910

Participant 2: submissions. If they are

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00:40:32.290 --> 00:40:40.650

Participant 2: ready to be accepted. So usually we go through the process, and after the 1st review process we think it should be revised.

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00:40:40.790 --> 00:40:51.650

Participant 2: Then we receive the r. 1 version, and this r. 1 version usually is then close to be accepted, at least for my journal, and then

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00:40:52.280 --> 00:40:54.760

Participant 2: this would also undergo statistical review.

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00:40:54.940 --> 00:41:22.160

Participant 2: and we have clear guidelines on how statistics should be provided, and how results should be presented, and sometimes it's a nightmare to get authors just respecting the straightforward statistical guidelines and rules. Be it like, if you provide male and female, the proportion of patients makes no sense to say 54% were male and 46 were

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00:41:22.370 --> 00:41:43.160

Participant 2: female. I mean, it's a no brainer, so you would not report both of them, because it's a redundant information, and I'm not really sure like putting too much emphasis

on how to provide patient summary would be very helpful, because I'm afraid that authors would not necessarily read all these details before they

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00:41:44.090 --> 00:41:46.279

Participant 2: finalize the manuscript.

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00:41:46.850 --> 00:41:54.819

Participant 2: because there's so many things to respect and to look at, and some of them do have a lot of experience. They publish in different journals.

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00:41:55.100 --> 00:41:59.759

Participant 2: and might not necessarily adapt it specifically to

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00:41:59.880 --> 00:42:06.230

Participant 2: a detailed journal. So I'm not really sure that there would be a way of how we could improve that.

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00:42:06.460 --> 00:42:12.389

Participant 2: I I think it's more what we would need to do again. Copy editing, I think, is a good target

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00:42:12.510 --> 00:42:23.199

Participant 2: where they should have a close look, if that is, lay language or not, and then, if that is not the case modified in a fashion that it is lay language, maybe suggesting a certain term

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00:42:23.730 --> 00:42:30.439

Participant 2: version and then having it validated, which is anyhow, the case by the authors before it is finally then ready for publication.

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00:42:31.520 --> 00:42:56.189

Karen Gainey: Right. So just some understanding, the author writes the patient summary, it goes repair for review. It gets to the copy editor. The copy editor has a look, suggest some changes. If they think it's not quite suitable, it goes back to the author, and the author has the opportunity to sign off if they're happy and satisfied with it, or suggest some other changes. Yeah, gotcha, yeah.

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00:42:56.190 --> 00:43:01.270

Karen Gainey: And the final acceptance actually is only done once it comes back from the copy editor.

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00:43:01.700 --> 00:43:14.869

Participant 2: Because once it's accepted, obviously we are not. We could not do any changes anymore because the articles accepted. So the the final step is indeed copy editing, and then I receive it back from the copy editor, and then I do the final acceptance of the article.

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00:43:15.280 --> 00:43:19.780

Participant 2: That is probably the moment where those changes should be done.

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00:43:20.540 --> 00:43:22.700

Participant 2: and you are raising a good point of

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00:43:23.020 --> 00:43:28.770

Participant 2: to the copy editor, and see if that might not be something there. You could concentrate on.

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00:43:30.750 --> 00:43:31.740

Karen Gainey: I can.

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00:43:31.940 --> 00:43:32.483

Karen Gainey: Yeah.

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00:43:34.080 --> 00:43:42.612

Karen Gainey: yeah, yeah, no, that. I'm just understanding the process because one of the things I'm trying to understand. If there's any barriers.

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00:43:43.240 --> 00:43:53.296

Karen Gainey: to changing the way plain language summaries are provided, or the guidelines. And so it sounds like, that's

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00:43:54.130 --> 00:43:56.540

Karen Gainey: So that's important to know.

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00:43:56.540 --> 00:44:05.289

Participant 2: I don't think there are any barriers you can put into the author's information whatever you want. The only problem is, if that information that is very laudable is really

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00:44:05.930 --> 00:44:11.199

Participant 2: touching those who are supposed to read it and to take it into account.

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00:44:11.680 --> 00:44:18.710

Participant 2: And again, I do not have the impression that a lot of authors read all the instructions from the beginning to the very end.

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00:44:19.310 --> 00:44:20.010

Karen Gainey: Yeah.

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00:44:20.010 --> 00:44:20.919

Participant 2: I'm pretty sure they don't.

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00:44:22.340 --> 00:44:31.909

Karen Gainey: That's not the 1st time I've heard that, and it really surprised me. I guess, being a student, I take it so seriously, and but I was so surprised.

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00:44:31.910 --> 00:44:57.549

Participant 2: When I started publishing the very 1st articles. I read them one by one, indeed, but I need to admit as well like nowadays. I would not do that anymore. I would submit the manuscript as it is, and then, if that comes back as a comment, it's not like in line with whatever is necessary, then I would modify, but I would not upfront. Check the details for all journals. Many of them are similar, obviously, but.

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00:44:57.550 --> 00:44:57.920

Karen Gainey: Right.

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00:44:57.920 --> 00:45:00.090

Participant 2: Some are, yeah, sometimes different.

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00:45:00.380 --> 00:45:11.960

Karen Gainey: Yeah, yeah, that I can understand that. Do you get any feedback from authors or readers of articles about?

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00:45:12.950 --> 00:45:20.040

Karen Gainey: any aspect of the or questions about about the patient summaries in particular.

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00:45:22.130 --> 00:45:30.909

Participant 2: no, no. But again, that is not the main part. What? What really is the key point of an article is the methods.

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00:45:31.537 --> 00:45:35.030

Participant 2: So that is where things might get stuck or not. Stuck.

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00:45:35.410 --> 00:45:45.860

Participant 2: Statistics obviously as well, which go very close together with methods, and all the rest is a formality, and obviously the the patient information is

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00:45:46.300 --> 00:45:50.549

Participant 2: is very helpful, but that will not be like a bottleneck, for

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00:45:50.750 --> 00:45:57.560

Participant 2: the publication is something that might be done at the very end. Last thing you do once you have written, the article is indeed

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00:45:57.700 --> 00:46:01.179

Participant 2: the Take home messages and and the the patient summary.

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00:46:01.840 --> 00:46:02.640

Karen Gainey: Sure.

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00:46:03.372 --> 00:46:09.147

Karen Gainey: All right. Now, that's really helpful. So I want to just talk about

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00:46:09.950 --> 00:46:13.689

Karen Gainey: Did you? Do you need a break at all. Okay.

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00:46:14.400 --> 00:46:35.330

Karen Gainey: we're getting to the end. So I just want to just ask a couple of things and then look to the future of where these kind of summaries might go. We've we've kind of covered this already, thinking of access to these kind of summaries. So I know you said your journals are. They're all open access.

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00:46:35.330 --> 00:46:37.750

Participant 2: No, only mine, no, only yours.

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00:46:37.750 --> 00:46:38.210

Participant 2: Mine is.

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00:46:38.210 --> 00:46:38.770

Karen Gainey: Access.

344

00:46:38.770 --> 00:46:46.931

Participant 2: And the others are, usually, let's say, normal functioning with the option of going for open access. If that is

345

00:46:48.120 --> 00:46:49.420

Participant 2: the author's wish.

346

00:46:49.720 --> 00:46:53.419

Participant 2: Okay? And in open science everything is open access. Yeah.

347

00:46:53.810 --> 00:46:57.030

Karen Gainey: Of course. So they're hybrid.

348

00:46:57.540 --> 00:46:58.090

Participant 2: Yep.

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00:46:58.370 --> 00:47:06.769

Karen Gainey: Model. Okay, so with yours, the patient summaries will be freely available.

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00:47:06.980 --> 00:47:12.740

Karen Gainey: But that won't necessarily be the case with the other journals.

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00:47:13.120 --> 00:47:14.300

Karen Gainey: Is that right?

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00:47:14.420 --> 00:47:19.489

Karen Gainey: No, okay. So you may not be able to to comment on those.

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00:47:22.250 --> 00:47:26.546

Karen Gainey: but so obviously, your patient summaries are

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00:47:27.160 --> 00:47:30.260

Participant 2: But that is yeah, generating.

355

00:47:30.260 --> 00:47:30.710

Karen Gainey: Yeah.

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00:47:30.960 --> 00:47:34.289

Participant 2: A huge bias being open access or not like, for example.

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00:47:34.768 --> 00:47:37.350

Participant 2: I I cannot tell you the the

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00:47:37.740 --> 00:47:42.730

Participant 2: the precise numbers. But European neurology gets like more than a million downloads every year.

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00:47:44.260 --> 00:47:46.660

Participant 2: We are getting 500,000.

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00:47:47.880 --> 00:48:05.060

Participant 2: For our journal, and then the other. Let's say, sister journals, oncology and focus. They get between probably 200 250,000. So, being an open access, we have with our journal the double, or or probably as much as the other 2 together.

361

00:48:05.550 --> 00:48:06.130

Karen Gainey: Hmm.

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00:48:06.130 --> 00:48:09.532

Participant 2: Especially if you look like for patient lay, whatever.

363

00:48:11.030 --> 00:48:15.229

Participant 2: It makes a huge difference to be open access or not.

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00:48:15.410 --> 00:48:17.799

Participant 2: or other times. You're not open access.

365

00:48:18.110 --> 00:48:20.820

Participant 2: Probably you don't need delay information

366

00:48:20.980 --> 00:48:31.220

Participant 2: because they will not get an access to it, and they will not probably pay €30, or whatever the single use. Access is for for

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00:48:31.950 --> 00:48:34.320

Participant 2: an article, and that is.

368

00:48:34.320 --> 00:48:34.640

Karen Gainey: Yeah.

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00:48:34.640 --> 00:48:41.099

Participant 2: I think, a very important point, especially if you address lay audience

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00:48:41.521 --> 00:48:43.079

Participant 2: how they could access the

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00:48:43.340 --> 00:48:49.710

Participant 2: the article if they will access the article or not. And that's a complete different story, obviously for an open access channel.

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00:48:50.550 --> 00:48:51.769

Participant 2: Well, yeah.

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00:48:51.770 --> 00:48:52.490

Karen Gainey: Exactly.

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00:48:52.490 --> 00:48:54.000

Participant 2: Downloads are coming from laid.

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00:48:55.420 --> 00:48:56.920

Participant 2: They read us.

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00:48:57.720 --> 00:49:00.540

Karen Gainey: Oh, okay, yeah, yeah.

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00:49:01.550 --> 00:49:24.470

Karen Gainey: because I know that some some journals have started to do something similar to the Cochrane database of systematic reviews, and have their patient summaries or plain

language summaries in a separate component or sorry section on their journal homepage with a searchable keyword component or sorry keyword.

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00:49:24.570 --> 00:49:28.140

Karen Gainey: searchable by keyword.

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00:49:28.900 --> 00:49:36.959

Karen Gainey: for the reason that they're not. Not. All articles are open access. What are your thoughts on that sort of idea?

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00:49:38.550 --> 00:49:39.340

Participant 2: I think, makes a lot of sense.

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00:49:39.340 --> 00:49:46.520

Participant 2: Hi, I I honestly, I have no idea how

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00:49:46.800 --> 00:49:53.040

Participant 2: somebody would get access to an article outside of using the like pubnet,

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00:49:55.010 --> 00:50:09.379

Participant 2: search system, or whatever or whatever you might use. Science director, whatever. I don't know. If, like Google would provide you with an access to all this, but they very frequently also go either to the Journal website or like pubmed.

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00:50:09.510 --> 00:50:11.830

Participant 2: And then you're back to this

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00:50:13.260 --> 00:50:21.890

Participant 2: would be interesting to see how they could access it, and probably make sense to have, like the patient summary available

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00:50:23.750 --> 00:50:27.008

Participant 2: outside of the open access or not open access.

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00:50:27.750 --> 00:50:30.750

Participant 2: Well, but then

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00:50:31.170 --> 00:50:47.269

Participant 2: I have doubts that somebody would be just happy with the let's say, 5 sentences. Probably they would like to look more into detail and get more information than just with this plain language summary, which I think is just a teaser.

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00:50:47.570 --> 00:50:53.039

Participant 2: and not necessarily the only information that should be getting out of an article

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00:50:53.800 --> 00:50:57.729

Participant 2: that is just too short, and I think not really helpful. I would expect.

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00:50:58.780 --> 00:51:22.300

Karen Gainey: Yeah, no, that's that's an interesting point. I guess it depends on what's in the patient summary. And one of the things that the readers of these summaries told us they use these summaries for was one of the things they used them for was to determine whether they wanted to read the entire article, whether

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00:51:23.580 --> 00:51:25.190

Karen Gainey: and relevant to them.

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00:51:25.250 --> 00:51:48.989

Karen Gainey: because we only spoke to people who had chronic medical conditions because they tend to be high users of of health information, particularly journals, and so they said they'll often read the summary as opposed to the abstract, to see if the pay the article was relevant, and they'll use them to look up new information about their medical condition or medication.

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00:51:48.990 --> 00:51:57.380

Karen Gainey: They might take it to their treating doctor or medical practitioner so very much in that kind of

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00:51:58.940 --> 00:52:05.150

Karen Gainey: cooperative sort of sense. So having access to the full article.

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00:52:05.600 --> 00:52:25.639

Karen Gainey: yeah, it is still important, particularly if they're only getting a few sentences that that wouldn't satisfy a lot of people. But they also said, the what's in it for me, aspect of the summaries was really important. So yeah, it was very interesting. It was quite an eye opener.

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00:52:28.190 --> 00:52:29.410

Karen Gainey: The other.

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00:52:29.550 --> 00:52:33.775

Karen Gainey: The other thing that some journals do, I know Wiley is

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00:52:34.290 --> 00:52:46.240

Karen Gainey: is one of the main ones they when we're talking about the copy editor having some input in the the summaries. I know Wiley offer an outsourcing option

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00:52:46.390 --> 00:52:59.500

Karen Gainey: for authors, to which is a paid service for writing what they call a plain language summary. What are your thoughts on that sort of service? And do you think that'd be

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00:52:59.710 --> 00:53:02.029

Karen Gainey: something your journal would.

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00:53:03.140 --> 00:53:07.550

Participant 2: Think makes sense to ask somebody. But

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00:53:12.090 --> 00:53:26.110

Participant 2: yeah, need to have a look how you you finance it. If that is an inside of the publication fee. If that is something additional you need to ask for. Obviously there are medical writers that take a huge amount of money for setting up an article, a manuscript.

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00:53:27.550 --> 00:53:29.920

Participant 2: Everything is possible.

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00:53:31.770 --> 00:53:53.259

Participant 2: probably like a probably it's 1 of the questions you have also in my later AI will be very helpful for this in the in the near future. I think you just put in the article and and ask Chat Gpt. Give me a plain language summary of this article, and that will probably be very appropriate and useful, and and get around all the different steps you might have

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00:53:53.440 --> 00:54:00.030

Participant 2: to take in order to get that a little bit more broader spread, and and really, for the targets

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00:54:01.290 --> 00:54:02.170

Participant 2: available.

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00:54:02.960 --> 00:54:07.430

Karen Gainey: Yeah, it's as though you read my mind. That's the next topic I want to talk about.

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00:54:07.430 --> 00:54:07.910

Participant 2: Okay.

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00:54:08.344 --> 00:54:15.730

Karen Gainey: The use of AI tools? Because obviously very topical. What do you think about that? And.

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00:54:16.560 --> 00:54:24.080

Participant 2: That is just like as we switch from typewriting with the typewriter to computers. That is the next step.

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00:54:24.540 --> 00:54:32.690

Participant 2: AI will do a lot of all these routine formal stuff, and I I think it's rather good thing.

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00:54:33.170 --> 00:54:40.400

Participant 2: like many of the articles sometimes are difficult to read if they are coming from a non native speaker.

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00:54:41.440 --> 00:54:48.259

Participant 2: and that might be a limited limitation, a bottleneck, because the content might be good.

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00:54:48.450 --> 00:54:49.410

Participant 2: But

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00:54:49.560 --> 00:55:09.679

Participant 2: the authors are unable to deliver the content, and the information that they would like to deliver. And AI can be very helpful to get through this problem and set it like in an understandable and logical and readable way. And I think it's just a matter of time that this is becoming standard. It's not like

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00:55:10.310 --> 00:55:17.370

Participant 2: fake data or or generating articles out of nothing. It's just like providing

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00:55:17.890 --> 00:55:35.150

Participant 2: generated information in an understandable and useful way, and one part of it will obviously be also plain language, and and you might even have a function. Translate me this article into plain language, which probably would get around the entire story of having some

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00:55:35.610 --> 00:55:41.150

Participant 2: parts of a scientific article dedicated to a general audience.

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00:55:42.160 --> 00:55:42.560

Karen Gainey: Yeah.

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00:55:42.560 --> 00:55:43.060

Participant 2: Okay.

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00:55:43.060 --> 00:55:49.470

Karen Gainey: And I guess then it would come down to what are the parameters or guidelines that you would have.

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00:55:51.493 --> 00:56:00.800

Participant 2: I would rather go instead of having somebody. A medical writer looking at this, having maybe a link to A AI.

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00:56:02.620 --> 00:56:05.339

Participant 2: But that provides you. Then, with a plain language.

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00:56:05.550 --> 00:56:08.492

Participant 2: let's say suggestion, and you can take it or leave it.

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00:56:08.910 --> 00:56:16.019

Participant 2: But that probably would be more helpful to have that available than any other solution, because for free and and might be

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00:56:17.080 --> 00:56:20.630

Participant 2: probably the easiest to apply option for. For this.

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00:56:21.330 --> 00:56:26.700

Karen Gainey: Okay? So in thinking of that decision, to get

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00:56:27.140 --> 00:56:33.370

Karen Gainey: if you're thinking of any changes to the patient summaries out of what we've discussed

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00:56:34.760 --> 00:56:38.790

Karen Gainey: going with an AI kind of tool over

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00:56:39.060 --> 00:56:43.589

Karen Gainey: an outsourced medical writer would be your preference.

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00:56:44.431 --> 00:56:50.219

Karen Gainey: So the considerations you mentioned cost. Would there be any other considerations that would sway your decision.

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00:56:50.220 --> 00:56:52.489

Participant 2: It is cost probably also the

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00:56:53.350 --> 00:57:22.739

Participant 2: the quickness of the approach, like copy editing. I think we're not too bad. With regards of the streamlining and the quickness of managing the articles in our family journal family, but it still can take 3, 4 days a week, sometimes to have the article copy edited, and that probably would be quicker to have AI. Having done it takes probably like a minute or 2 min, if not, and probably you would get in most cases usable.

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00:57:23.410 --> 00:57:24.230

Participant 2: Summary.

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00:57:25.960 --> 00:57:43.009

Participant 2: Is the experience I have with AI usually provides you with what you are waiting for, with the reasonable quality and acceptable quality, and that is probably the quickest way, if that is not nowadays already done by a lot of authors. Anyhow.

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00:57:44.050 --> 00:57:48.650

Karen Gainey: Do you think I'm think it's? How likely do you think it is that that's the way.

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00:57:48.650 --> 00:57:52.180

Participant 2: Very likely. So we we recognize it.

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00:57:53.180 --> 00:57:59.509

Participant 2: I'm involved in the journal. I'm involved also in the abstract selections for the annual meeting of the Eau.

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00:57:59.890 --> 00:58:03.819

Participant 2: and especially from those countries who obviously are not native speakers, and

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00:58:04.000 --> 00:58:11.119

Participant 2: that for, let's say, decades, we're struggling with providing a real abstract. Nowadays. It's a.

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00:58:11.410 --> 00:58:21.429

Participant 2: The English is no more a bottleneck, and the terms are no more bottleneck, and you see that most of the abstracts we receive are, let's say.

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00:58:21.610 --> 00:58:30.600

Participant 2: edited by AI, and probably many of these submissions receive also are edited by AI. Some are also like fraud, and you

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00:58:30.790 --> 00:58:42.840

Participant 2: it once more. The methods usually are able to recognize this, and these have been straight rejects. But this is becoming like a usual tool, as was the computer writing instead of the typewriter writing a few years ago.

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00:58:43.520 --> 00:58:52.429

Karen Gainey: Right? Yeah. And I mean, we already really have AI tools with things like grammarly prowritingaid that we've had for some time. It's the next generation.

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00:58:53.487 --> 00:58:57.252

Karen Gainey: Actually, I just this is kind of

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00:58:58.200 --> 00:59:01.990

Karen Gainey: part of my questions, but also interested to

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00:59:02.350 --> 00:59:16.009

Karen Gainey: to hear your thoughts on some of the people. I spoke to that read plain language, summaries that were for whom English was not necessarily their 1st language, or or were multilingual

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00:59:16.120 --> 00:59:22.080

Karen Gainey: mentioned, the use of medical jargon being a difficulty.

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00:59:22.320 --> 00:59:25.980

Karen Gainey: Can I get your thoughts and perspective on on that.

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00:59:27.960 --> 00:59:33.249

Participant 2: That's what I meant. At the very beginning, where I said to.

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00:59:33.530 --> 00:59:45.619

Participant 2: I was writing articles, together with other authors, and trying to be as avoid any, any jargon, but some of them are coming so natural for us that they are still difficult to understand.

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00:59:47.550 --> 00:59:53.530

Participant 2: And you really need to take a step back if you're a physician

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00:59:53.960 --> 01:00:01.709

Participant 2: and write an article to really avoid all these terms that are too specific and difficult to understand, and then it's getting

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01:00:02.310 --> 01:00:11.889

Participant 2: even more complicated like, do that in German or French, for example, because you might have some German medical terms, English terms, obviously, and then some

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01:00:12.050 --> 01:00:22.469

Participant 2: more broader general terms for anatomical structures, for example, and making sure that these are understood by everybody, is quite a challenge.

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01:00:22.730 --> 01:00:23.670

Participant 2: And could you.

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01:00:23.670 --> 01:00:28.990

Karen Gainey: An example. If if you that's not asking too much.

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01:00:28.990 --> 01:00:39.849

Participant 2: Like, I was working quite a lot on the anatomy of the prostate, for example. And there's different structures. And you can talk about the neurovascular bundle, for example.

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01:00:40.140 --> 01:00:42.360

Participant 2: which is

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01:00:42.570 --> 01:00:55.499

Participant 2: a very commonly used term for us as a urologist. But I'm not sure that this would be something that lay would easily understand. You would then talk about bringing the nerves

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01:00:55.610 --> 01:00:56.950

Participant 2: and the vessels.

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01:00:57.090 --> 01:01:13.569

Participant 2: But vascular, for example, is nothing they would understand. Even so neuro and vascular is something that is not very, very sophisticated. It might already be too sophisticated. And this is like, you can talk about the bladder neck, for example, which is

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01:01:15.390 --> 01:01:20.460

Participant 2: from probably language level a proper term.

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01:01:20.730 --> 01:01:23.699

Participant 2: but I'm not sure a patient would understand what the bladder neck is.

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01:01:25.190 --> 01:01:26.410

Karen Gainey: Great example. Yes.

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01:01:26.410 --> 01:01:28.850

Participant 2: So you would rather talk about the bladder outlet.

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01:01:29.640 --> 01:01:30.310

Karen Gainey: Yes.

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01:01:30.310 --> 01:01:31.510

Participant 2: Than the bladder neck.

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01:01:32.110 --> 01:01:42.780

Participant 2: because you would not necessarily know how the bladder detail and anatomical details are, and like terms you, you might even translate them to German.

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01:01:42.950 --> 01:01:51.559

Participant 2: and they the true German terms without using any Latin origins or Greek origins. Still, they are too specific

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01:01:51.730 --> 01:02:00.719

Participant 2: and anatomical. For example, then for for a link, and sometimes, indeed, like the detail that makes a difference, to have it understandable or not.

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01:02:01.590 --> 01:02:03.280

Karen Gainey: Bye, understand what you mean.

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01:02:03.280 --> 01:02:07.170

Participant 2: Quite a challenge to really get to a patient

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01:02:07.700 --> 01:02:10.630

Participant 2: level where everybody understands what you're talking about.

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01:02:11.410 --> 01:02:16.480

Karen Gainey: Right. It seems to come down to not making assumptions, perhaps about.

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01:02:17.460 --> 01:02:18.410

Karen Gainey: Thinking about it.

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01:02:18.410 --> 01:02:20.030

Participant 2: It's just like being really.

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01:02:20.030 --> 01:02:20.670

Karen Gainey: Step back.

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01:02:20.670 --> 01:02:27.750

Participant 2: Step back. That's it. And really think, if I would not have any medical background, would I be able to understand that or not?

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01:02:27.860 --> 01:02:33.099

Participant 2: And it is, takes nothing at all to think

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01:02:33.460 --> 01:02:36.490

Participant 2: you're out of medical terms, but you're still very much into it.

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01:02:37.120 --> 01:02:42.680

Karen Gainey: Yeah, yeah, great just just last one.

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01:02:44.410 --> 01:03:01.649

Karen Gainey: I'm sorry. I don't remember. I did look at your your guidelines before. I've looked at them a lot of times. But I just don't recall if your journals offer other than the text-based, patient, summary other

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01:03:02.452 --> 01:03:05.709

Karen Gainey: formats, such as video or graphical.

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01:03:05.940 --> 01:03:08.219

Participant 2: We are working on the visual abstracts.

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01:03:08.590 --> 01:03:09.050

Karen Gainey: Yup!

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01:03:09.050 --> 01:03:19.044

Participant 2: And also on, let's say, some podcast, summaries or or or other. Let's say, ways of of distributing the information.

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01:03:19.670 --> 01:03:29.149

Participant 2: But there we have probably the same issue that we have with the patient summaries that how we can have them standardized, and all at the same quality.

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01:03:29.480 --> 01:03:33.340

Participant 2: and not having then somebody professionally doing that.

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01:03:33.610 --> 01:03:45.679

Participant 2: So if you ask the authors to provide a visual abstract that could be excellent and could be unusable, and if you ask them to provide you with a short podcast

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01:03:46.490 --> 01:03:51.839

Participant 2: summary of their their article. It might be excellent. It might be completely unusable.

493

01:03:51.950 --> 01:04:15.150

Participant 2: So we are well aware that nowadays. Indeed, it's not just like black and white, some text on a on a white background. To communicate and to distribute information. Probably that's even outdated, but to have it as reproducible and as easily accessible and as good as this constant quality as it is with black and white.

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01:04:15.750 --> 01:04:24.570

Participant 2: That is what is difficult and maybe also AI will be helpful here in the near future. Just provide me with a 2 min podcast of this information.

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01:04:25.232 --> 01:04:27.839

Participant 2: or a visual abstract of this information.

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01:04:28.150 --> 01:04:37.909

Participant 2: Maybe that is also a way around it. And again, it's not like about fraud or whatever. It's just like being able to provide detailed information in an easy.

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01:04:38.190 --> 01:04:46.140

Participant 2: reproducible, and understandable way, and I think that is what where I is really helpful, or will be helpful in the near future.

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01:04:47.570 --> 01:04:49.029

Participant 2: It's already locked up. Yeah.

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01:04:49.700 --> 01:04:54.220

Karen Gainey: Yeah, yeah, more formats, more options. Yeah.

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01:04:54.797 --> 01:05:03.349

Karen Gainey: Okay. Well, just to wrap up, maybe other than AI, what do you think is the future of patient summaries?

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01:05:06.090 --> 01:05:18.830

Participant 2: I think a good thing is that patients get more and more involved, most of them. But then, as you said also, it depends very much on where they come from, what the culture is, their background, their motivation.

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01:05:18.980 --> 01:05:39.219

Participant 2: and some will take a huge benefit out of it, others will not. But then I think we would also need to think about having other medias taking up the information like, if you would not only have your information inside of a scientific journal, but maybe also like a

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01:05:39.230 --> 01:06:00.740

Participant 2: normal newspaper or the Internet. I think that is where it becomes very helpful to get in this direction. So. Indeed, the term patient summary, might not necessarily what is the only aim behind is just like the more broader general audience that might be targeted, and the more you have that information available

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01:06:00.970 --> 01:06:05.310

Participant 2: and spread, the the more you will get. Probably to that level.

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01:06:05.480 --> 01:06:10.649

Participant 2: And some information we publish is probably relevant for these

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01:06:10.960 --> 01:06:26.079

Participant 2: audience as well, and it would be good that some of this information is indeed spread, but you might then also have a press release associated to it inside of the scientific association. But the more channels you use, probably the better it is, and

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01:06:26.570 --> 01:06:36.769

Participant 2: that is probably also one of the targets we might want to go for in the near future together, like a broader audience, at least for some of the information we provide.

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01:06:37.580 --> 01:06:49.992

Karen Gainey: Yeah, no understood. Do you mean? Just so I understand. Do you mean encouraging authors? Or the journal itself, using things like social media?

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01:06:50.470 --> 01:06:57.140

Participant 2: That. That's what we do already. It's more like getting the normal media

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01:06:58.770 --> 01:07:03.909

Participant 2: an access to that information, because the the

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01:07:05.540 --> 01:07:18.081

Participant 2: the people being inside of a New York Times, or or whatever you sit in a daily, whatever you have as a journal in Australia, that they would be able to capture that information being

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01:07:18.630 --> 01:07:32.490

Participant 2: let's say, attracted by that information because they might not necessarily be super scientific neither. But they might capture it and see, okay, that's interesting. And why not having an article or a paragraph on this information?

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01:07:32.680 --> 01:07:38.520

Participant 2: And if you have indeed understandable information coming from our journal

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01:07:38.660 --> 01:07:42.649

Participant 2: outside of our journal, then this, this might be something

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01:07:42.830 --> 01:07:48.219

Participant 2: that you can achieve, and and probably an interest of of everybody, at least for some of the publications we.

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01:07:50.560 --> 01:08:00.580

Karen Gainey: Right? Well, it sounds like you've really actually thought about this a lot. Thank you so much, I guess, just to wrap up. Is there anything any barriers or facilitators

517

01:08:01.090 --> 01:08:03.380

Karen Gainey: that we haven't covered, that you think.

518

01:08:03.740 --> 01:08:04.820

Participant 2: Think it was

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01:08:05.710 --> 01:08:16.609

Participant 2: interesting discussion. So I also learned a lot. Thank you very much for the opportunity. So it's interesting to always get some feedback and then input from outside some stuff. We do not necessarily.

520

01:08:17.434 --> 01:08:23.239

Participant 2: Look at it. And yeah, gives you another focus. Very interesting. Thanks. A lot.

521

01:08:23.240 --> 01:08:38.470

Karen Gainey: Good. Thank you. Just 2 2 things I want to ask you. Would you? That I'm offering to everyone I I talk to. Would you like to see the transcript of this to see to check it at your.

522

01:08:38.479 --> 01:08:40.223

Participant 2: No, the transcript time.

523

01:08:40.660 --> 01:08:41.000

Karen Gainey: Context.

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01:08:41.000 --> 01:09:10.880

Participant 2: You do whatever you want like to do with it? If you have, why, why transcripting other questions feel free to come back to me, and I might specify some stuff that is maybe not clear what I was checking. Actually in the survey. It would be interesting to

get the final information like from all the interviews you did. If ever you you have that available and I check the box for further research. I I said, no, just to make sure that I'm not like overwhelmed by

525

01:09:11.069 --> 01:09:28.010

Participant 2: by emails and invitations for stuff that is outside of my interest. But if you have anything else feel free to contact me. I'm happy to contribute or do something else. If that is the same direction I just like, avoid to agree to whatever. And when you're just like spam with mails.

526

01:09:28.010 --> 01:09:28.370

Karen Gainey: Oh, yeah.

527

01:09:28.370 --> 01:09:30.859

Participant 2: Information. And you will, yeah.

528

01:09:33.580 --> 01:09:49.970

Karen Gainey: If you like other editors, you'll be very busy because you're not just doing this. So I totally appreciate that. And I really appreciate you taking the time? Do you know of any other editors that you could recommend that might be interested in participating.

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01:09:49.970 --> 01:09:53.229

Participant 2: And you you have.

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01:09:54.200 --> 01:10:05.560

Participant 2: Obviously you can check the the 3 others from the the main journal. You can find them easily. Yeah. If not, there's John Ward from the

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01:10:06.044 --> 01:10:11.885

Participant 2: American Journal, the Journal of Urology, and they have also an open access, which is I think,

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01:10:13.800 --> 01:10:16.740

Participant 2: American practice or something with John Ward. His name.

533

01:10:17.140 --> 01:10:17.470

Karen Gainey: Okay.

534

01:10:17.470 --> 01:10:22.030

Participant 2: Like. It's the the correspondent from from my position

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01:10:23.130 --> 01:10:26.905

Participant 2: the British Journal of Urology they have also. I I think it's

536

01:10:28.800 --> 01:10:30.900

Participant 2: What's the the editor in Chief

537

01:10:35.490 --> 01:10:36.200

Participant 2: Bank.

538

01:10:37.010 --> 01:10:43.760

Participant 2: Well, you will find it. They have compass, which is the Open Access journal, if ever you're interested. So British Journal of Urology compass.

539

01:10:44.400 --> 01:10:49.520

Participant 2: and you might check with them if they would be interested, if that is of any help, and then.

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01:10:49.520 --> 01:10:49.950

Karen Gainey: Okay.

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01:10:50.350 --> 01:10:52.559

Karen Gainey: Yep, that's a Uk.

542

01:10:53.023 --> 01:10:58.590

Karen Gainey: Is it? Okay? If I mention your your name that they yeah.

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01:10:58.750 --> 01:11:17.540

Participant 2: And then, probably coming back to the issue we had we had, and that might be more interesting for you than going for another English speaking journal. You might want to go to the national journals. Maybe the German it's called the or the Spanish or the French

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01:11:18.418 --> 01:11:25.109

Participant 2: have a look on what they have ongoing like in countries where

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01:11:26.040 --> 01:11:28.060

Participant 2: paper is not necessarily published in

546

01:11:28.270 --> 01:11:35.360

Participant 2: English, but in German. And you might maybe get some more specific input on that outside of the

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01:11:35.550 --> 01:11:36.900

Participant 2: English language.

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01:11:37.950 --> 01:11:40.790

Karen Gainey: If I could translate it into English.

549

01:11:41.920 --> 01:11:48.750

Karen Gainey: that. And if if the person could speak English, yeah, I hadn't thought of that, because I've.

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01:11:48.750 --> 01:11:53.080

Participant 2: Probably will be. Those who run the journals probably will be able to speak English, but they might get

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01:11:53.490 --> 01:12:00.950

Participant 2: some more, input or might provide you with some more input on on what might be necessarily great idea

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01:12:00.950 --> 01:12:05.440

Participant 2: language, and how they might go around the the problem with the lay language.

553

01:12:05.880 --> 01:12:09.639

Participant 2: the plain language, if that is an issue or not. Again.

554

01:12:10.020 --> 01:12:12.240

Participant 2: at the beginning, when I was studying

555

01:12:12.520 --> 01:12:20.350

Participant 2: using French or German or English, I'm not sure I would have been able to recognize what plain language would be or lay language would be.

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01:12:21.300 --> 01:12:24.229

Karen Gainey: Yeah, okay, thank you so much. I appreciate that.

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01:12:24.750 --> 01:12:34.540

Karen Gainey: Okay, alright, I will let you go. We've just gone a bit over the hour. But thank you again. I really appreciate your time. And it's been really helpful, so helpful.

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01:12:34.540 --> 01:12:35.025

Participant 2: Okay.

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01:12:35.510 --> 01:12:37.086

Karen Gainey: Okay, have a great

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01:12:37.480 --> 01:12:39.029

Participant 2: Good evening. Bye-bye.

561

01:12:39.030 --> 01:12:40.110

Karen Gainey: Bye.