AMERICAN MEDICAL WRITERS ASSOCIATION AMWA JOURNAL V37 N4 / 2022

THEME ARTICLE

What About the Audience?

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Information may be provided to a broader range of consumers. No longer will results of studies be limited to regulators and scientific/medical cognoscenti. With greater access to posted documents on a variety of portals, the public will seek and access information that is important for informed decision-making. The patient will have a stronger voice in determining their treatment, and this will extend to end-of-life decisions. Social media will amplify results and will spread misinterpretations and poor-quality data. *Caveat emptor*!

Are you scared or excited (or both!) by the increased use of social media to communicate scientific information? What can medical writers do to help stop the spread of misinformation?

Samuel Entwisle: I would say both! I'm not very comfortable with social media myself, so the idea of engaging with these platforms and communicating medical information on a regular basis is a bit anxiety-inducing. But I think this can be an important role for medical writers, especially as rabbit holes of misinformation on social media can make finding accurate information difficult. I do think there is a great opportunity for collaboration between medical writers and online content creators who are savvy with how to get good social media engagement. And we should make as many plain language materials as possible free, available, and easy to discover online so that content creators can access them. I think it's essential to build increased literacy about clinical research, and social media will have to be a big part of that.

Zack Fey: I'm with Sam on this one. Regarding the surge in the sheer quantity of avenues to access scientific information, I could not be more excited. But, when it comes to social media specifically, I am more apprehensive. There is a seemingly infinite number of posts, articles, photos, and videos competing for attention on social media. And I have found myself and others skip over a scientific article in favor of something that takes less effort to read or is something more immediately captivating. It will be a challenge to create interesting and accurate scientific content that is able to compete on the mainstage of the ever-expanding universe that is social media.

Samuel Entwisle: Absolutely. If you're trying to compete for attention on social media, the way to do that is by having big, flashy, or controversial headlines, not through nuance or data that is presented in a neutral way. This is the world we live in. But we still need ways to counteract the bad information that tends to go viral, to "develop antibodies" against it, you could say. Maybe it's rare that a piece of neutrally presented clinical trial information will explode on Twitter. But maybe that's okay! We can still make it as easy as possible for people who are actively seeking this type of information to access it, and then measure our success by making sure that people are in fact accessing it. Some clinical trial sponsors are starting to think about this more seriously now, but we can definitely do better.

Kimbra Edwards: Social media plays an extremely powerful role in people's lives today. For better or worse, many turn to their social media feeds for information on a variety of topics, including scientific information. Scientific information communicated through social media often uses catchy headlines and abbreviated formats, which serve as a quick and convenient way to consume information in a world where it feels mandatory to stay in-the-know and offer an opinion on a given hot topic. As my colleagues have

ISSN 2163-5315

stated, a primary concern with social media is the spread of misinformation. Misinformation seems to spread on social media either because important nuances aren't captured, or someone uses the platform to speak on a topic without fully understanding it.

So, what can medical writers do to help counteract misinformation? One option is to use your own social media to spread accurate scientific information, either by writing your own posts or simply sharing posts from verified sources to increase their visibility. If social media isn't your thing, another option is to utilize the appealing aspects of social media in your work. This could include using concise language, explaining the "so what?", and exploring alternative formats such as videos.

How can medical writers enhance the quality of documents made available to the public?

Zack Fey: As medical writers a (or dare I say, the) key skill we are always improving is our ability to communicate. Communication is important in every aspect of life and especially when creating something for others to read and engage with. Getting to know the audience we are writing for helps first and foremost. After that, we are tasked with putting words on paper in a way that best speaks to the target audience. It is easy to accidentally lose sight of your audience from behind your computer screen and favor your own grammar, structure, and clarity preferences. But that is the everyday challenge we happily accept.

Samuel Entwisle: Yes, getting to know our audience is so important, and it's easier said than done. I think Zack is right on that we must have a degree of humility about it and not get too married to our own opinions about what good writing looks like in other contexts. User testing can help a lot with that. And I think life experience helps as well, which is another reason why diversity in culture, race, class, gender identity, and so on is so important for good medical writing. I also really value close collaboration with editors and graphic designers. You could be writing the clearest, best sentences in the world, but if they are not formatted in a friendly way, or if they're not accompanied by graphics that draw you in and lead you along, then I think you'll be missing opportunities to engage with your target audience.

Kimbra Edwards: One way for medical writers to enhance the quality of documents written for the public (or any audience, really) is to write them in plain language. Utilizing plain language best practices allows you to communicate more effectively. Another way, as stated above by my colleagues, is to consult with others who have expertise outside of yours. These experts might include graphic designers, editors, or patients. Lastly, it is important to actually apply the learnings from these experts (for example, don't ask patients for their feedback to simply check a box).

What are some strategies medical writers can use to ensure data and information are communicated accurately but still in a way the reader can understand? How do you best balance scientific accuracy with clarity?

Samuel Entwisle: This is always the challenge, right? I write a lot of plain language summaries of clinical trial results, and one thing I try to tell myself is there's no such thing as perfection. It helps to approach these plain language materials with a sense of priorities. What are the most important take-home points that we need to convey? In my case, this would usually be the results of the primary endpoint of the trial, and maybe a secondary endpoint, plus some key safety data. Once we now have this in mind, we can work backwards and ask what the reader needs to have a great understanding of these take-home points. If a certain concept is critical for this understanding, we can spend some time and really explain it. If not, we can give it more superficial treatment or omit it entirely. But there will always be trade-offs, and people may not always agree on how to navigate them.

Zack Fey: I am generally a proponent of presenting something in the most concise way possible, especially in plain language documents. Recently, I have been writing a lot of 2-page plain language protocol synopses for clinical trials based on the European Union Clinical Trials Regulation. When space is at a premium, I may omit the explanation of a term entirely instead of including a superficial explanation that may confuse the reader more. In the future, we may be able to offer an optional third page of the synopsis with a glossary of terms. Clarity and accuracy can easily coexist under the right conditions.

Kimbra Edwards: Like Sam, I find remembering the bigger picture key. What exactly do you want readers to walk away with? Writing with this in mind, it becomes more obvious how best to position data and other information. When considering the balance between scientific accuracy and clarity, I also think about the balance between complete transparency and thoughtful data selection. Of course, it is important not to cherry pick positive data, but it is also important to not overwhelm the reader with copious amounts of data

that might be misinterpreted. For example, patients and the public tend to assume that all adverse events are caused by the study treatment, even when it is clearly explained that this is not the case. This can give the impression that the study treatment is less safe than it is. Thus, writers of plain language summaries of clinical trials should consider only including possibly related adverse events above a thoughtfully determined frequency threshold.

What are some ethical concerns when writing for patients and the public? How can we as writers best mitigate these concerns?

Zack Fey: One of the biggest ethical concerns is the source of funding and information. Medical writers must accurately, fully, and nonpromotionally convey scientific information to patients and the public while still meeting the sponsor's requests and needs for a given project. Often, the needs of the public and a sponsor can seem at complete odds with one another. With a title like "medical writer," someone may think all we do is sit at a keyboard and type about science. What I've learned is that while writing is a large part of the job, learning to successfully compromise on complex topics to provide useful documents is more the task at hand. A medical writer must take seriously the duty of being one of the checks and balances to all scientific information that reaches the public.

Samuel Entwisle: Compromise is an important skill for medical writers, especially those balancing the interests of trial sponsors and patients. One thing that can help a great deal is defining detailed processes and templates that the writer and the clinical trial sponsors agree to. This can prevent some difficult situations when deciding, for example, which endpoints or safety data to include in a plain language summary, or whether to refer to a drug by its trade name. Mutually agreed-upon processes and templates can help to keep plain language deliverables nonpromotional. Ultimately, increased literacy about health and clinical research is in everyone's interest.

Kimbra Edwards: Much of the "friendly friction" we encounter with sponsors arises from disagreements on data inclusion and the overall messaging of the results because we strive to present results in a nonpromotional, neutral way. Luckily, we work with collaborative sponsors that respect the CISCRP's independent positioning and patient-centered approach, so typically this friction is resolved after a brief explanation of why we do things the way we do them. It is important that other medical writers working with sponsors (or other stakeholders with varied interests) feel comfortable enough to uphold the high ethical standards that come with writing for patients and the public.

What are the benefits and challenges of user-testing documents with the intended audience (public, patients, health care providers, etc.)?

Samuel Entwisle: I think the benefits of user testing are clear. In general, getting feedback from your intended audience is essential for a writer. It is crucial to get input from all stakeholders, especially patients and the public, regarding how information about medicine and clinical research is communicated. We are lucky enough to work at an organization in which almost every deliverable we create is user tested by a review panel of patients, patient advocates, and members of the public. This gives us confidence that we are creating high-quality deliverables, and it has also led us to accumulate a great body of knowledge and the best practices about how to best communicate about clinical trials in a clear and humane way. One challenge, I think, is that we want to avoid over-correcting. For example, if one person makes a comment that they don't like how a certain concept is explained, but 9 people like it best the way it is but say nothing, we want to make sure we don't fix what isn't broken.

Zack Fey: A challenge I see with user testing is that the public, patients, and health care providers can provide feedback that is too general. A comment such as "this is good," for example, isn't very helpful. Like Sam said, user testing is great to build the "confidence that we are creating high-quality deliverables," but the best feedback takes time and active engagement from the reviewers. Finding reviewers that are willing to give up their time to provide quality feedback that will translate into an improved deliverable is no easy task.

Kimbra Edwards: Another challenge with user-testing documents with their intended audience is the extra time it takes. There is no doubt that the feedback obtained by user testing can be valuable, but with strict deadlines, it can be a real challenge to fit meaningful user testing into a project timeline. One strategy is to start your project as early as possible. Plain language trial results summaries can have strict posting deadlines. To meet these deadlines and still have time for user testing, we have started drafting the summaries based on the tables, figures, listings document instead of the clinical study report, which can often take much

longer for sponsors to finalize. If you can't start your project any earlier, another strategy is to start recruitment for the user testing far in advance. Having your reviewers in place and ready to go, with clear deadlines and expectations communicated, is very helpful.

Author declaration and disclosures: *The authors note no commercial associations that may pose a conflict of interest in relation to this article.*

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BIOSUMMARIES

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Samuel Entwisle is a Medical Writer at the CISCRP. Entwisle helps to create plain language trial results summaries and plain language summaries of publications among other lay-language resources. Entwisle earned his BS in Biochemistry from the University of Maine and his PhD in Molecular and Cellular Biology from the University of Washington.

Zack Fey is a Medical Writer at the CISCRP. Fey helps create easy-to-understand trial resources, including plain language protocol synopses and plain language trial results summaries. Fey earned his BS in Economics from George Washington University and did a postbaccalaureate premedical program at Tufts University.