Medical Communications and Writing for Patients

Editorial

Dear all,

In this edition of *Medical Writing*, we have a report from the inaugural "Meet & Share" session from the Communicating with the Public Special Interest Group (CwP SIG). EMWA's SIGs host these sessions throughout the year, encouraging open and honest discussion between medical writers on a variety of topics (identified and advertised ahead of the session). EMWA is an incredible community with a lot of very experienced and talented medical writers who never cease to amaze me with their generosity of time and advice, so I strongly encourage you to look out for the Meet & Share sessions and get involved!

For its first meeting, the CwP SIG held an open forum to introduce the new SIG, explain what writing for the public means, offer examples of the areas medical writers can explore and be involved in, and then answer any questions that the attendees might have. The objective of the session was to formally introduce the SIG, to share its objectives, and to get input from the attendees to help refine our aims. The key topics discussed at the session are summarised in the excellent report from Sampoorna Rappaz, a member of the SIG.

I hope that you enjoy Sampoorna's article as much as I did, and in the meantime, stay safe and sane – enjoy the sunshine (if you have any!), and see you in the December issue!

Bestest,
Lisa

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Introducing a new EMWA Special Interest Group: Communicating with the Public
A report of the group's first Meet and Share

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The Communicating with the Public Special Interest Group (CwP SIG) held its first Meet and Share session as an open interactive forum on October 25, 2022. The session consisted of presentations by SIG Chair Lisa Chamberlain James and panellists and SIG volunteers Sara Ferrão, Adeline Rosenberg, and myself, followed by a thought-provoking discussion with an audience of about 30 attendees. Lisa introduced the SIG and was the session moderator. The panellists gave a brief overview of the types of public-facing documents, spread across the main specialisations within medical writing, that a professional medical communicator could be expected to develop. The objective of the session was to formally introduce the SIG, to share what we want to do, and to get input from the audience to help refine our aims. The key topics discussed at the session are summarised below.

CwP SIG's main goals
The main goals of the CwP SIG are:
- To educate and inform EMWA members about the crucial and expanding field of medical writing that is "communicating with the public". It requires a specialised skill set and a more nuanced understanding of the audience than that required for other types of medical writing.
- To engage with regulatory agencies to highlight the importance and value of trained medical communicators when developing public-facing materials.
- To interact with patient advocacy groups and specialists to highlight the added value, in terms of scientific and communication know-how, that medical communicators can bring.
- To involve industry colleagues from other departments (for example, patient centricity, public relations) to create awareness about plain language writing and the advantages of engaging a trained medical communicator for their deliverables.

Communicating in plain language is a widely useful skill
Apart from developing clinical study-related documents solely meant for regulators, regulatory writers also need to be able to communicate complex details about the clinical study to study participants, who are most likely to be non-specialists and thus would need text written in plain language and simple graphs. Some of the regulatory documents that would require plain language writing skills include the information consent form, the lay summary of clinical study results, the product information leaflet (or package insert), and the summary of safety and clinical performance (for a medical device). These documents must be prepared following the guidelines and regulations stipulated by regulatory agencies and ethics committees. The Declaration of Helsinki mandates that clinical study results must be made accessible to the public,[1] but accessibility implies more than being just made available on an online portal; it implies making results understandable and usable. Effective plain language writing in regulatory documentation can help improve patient recruitment, engagement, and understanding.

In scientific communication, there are two major kinds of plain language documents that can be developed in association with a primary manuscript. One is a brief jargon-free summary

of a peer-reviewed publication called publication-associated plain language summary (PLS). It is embedded either within the main manuscript or in the supplementary materials. Concise, text-only PLS can be indexed on PubMed. The other is a standalone, secondary publication called the plain language summary of publication (PLSP), which is often developed for a patient audience (and can include the patient perspective and patient-authors). Currently, PLSPs are published by Future Science Group journals. Visual communication deliverables associated with a manuscript, such as slide decks, graphical abstracts, and video abstracts, would also be more effective if presented in a simplified and clear format.

Medical journalism, also called health journalism, involves communicating medical news, research, and scientific advances to the public. While medical writers engaged by clients to craft news reports or press releases cannot call themselves journalists (as journalists must be truly objective and without a shadow of a conflict of interest in their reporting), they can become independent science journalists or writers by learning journalistic writing techniques. These medical writers, like traditional medical journalists, can then write for newspapers, consumer publications, e-zines, radio, and television. Rigorous medical writing with a journalistic style would improve the quality of the medical and health content on the internet, social media outlets, and mass media. Journalistic writing has many uses within the regulatory writing and medical communications landscapes: crafting clinical study backgrounders, Q&A, study newsletters, spokesperson bios, slide decks on study, press releases, website content, reports (like this one!), blogposts, newsletters, social media posts, feature articles, profiles and interviews, infographics, and a myriad of patient-facing material (print and online).

Medical editors specialising in plain-language editing and fact-checkers with training in how news organisations fact-check content also play a crucial role in ensuring that the information being communicated to the public is trustworthy, i.e., the content is relayed truthfully and the sources are reliable and competent. Therefore, medical editing (that focuses on audience, purpose, coherence, and clarity) and fact-checking (that focuses on accuracy, precision, compliance, consistency, and completeness) are the final two critical pieces that solve the "communicating with the public" puzzle to produce a balanced, understandable, and useful document.

Role of the medical communicator

Following are some of the actions a medical communicator must take when developing a document meant for the public:

- Understand, use, and advocate for plain language writing
- Provide assurance of the credibility, quality, and compliance of plain language documents
- Manage expectations about differences between scientific writing and plain language writing
- Understand and implement health literacy principles
- Implement workflows that make fact-checking easy and efficient

Challenges faced when writing for the public

The problems encountered when assessing and developing deliverables for the public were the major focus of the discussion that followed the presentations. Some of the general issues raised were: ethics, appropriateness, and usability of patient and public involvement (PPI) in healthcare research; lack of formal assessment of readability of lay language summaries; and "spinning" and the wrongly implemented notion of "fair balance" in medical journalism. The specific challenges when it comes to writing for the public include: precision in cross-cultural translation of lay language summaries; determining the readability of graphs; misalignment between the language and the purpose of the document; getting different stakeholders to agree on the benchmarks for a plain language document; and eliminating blind spots innate to medical writers who have been writing for specialist audiences.

Communicating effectively with the public

requires the writer to be empathic; this is a difficult skill to master and a tough concept to teach when working with teams who haven't done this before. Medical communicators would need to move beyond readability, ensure that patients understand the text on first read, and write in a way that allows patients to feel the writer's "voice". The session ended with all agreeing that writers can do more than share medical information: they can send their readers verbal hugs and there's nothing wrong with that at all!

The CwP SIG thanks all the attendees for their insightful contributions to the discussion. The session was recorded and will be available on the EMWA website.

Disclosures and conflicts of interest
The author declares no conflicts of interest.

References

1. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013;310(20):2191–4. doi:10.1001/jama.2013.281053

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