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Medical Writing

Writing for patients

The first thing we must say is a huge "thank you" to **Dr Juan Garcia Burgos** and **Mr Paul Blake** for taking the time in an unprecedentedly manic year for the EMA to write a foreword for this issue of *Medical Writing*. The fact that they have prioritised this in the middle of the EMA relocation shows the huge commitment of the agency to engage with EMWA and the medical writing community in general, and the importance that the EMA places on transparency and providing quality information to patients and the general public. We are honoured and grateful to Juan and as a community look forward to continued communication and collaboration with the EMA on this crucial topic.

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When we started thinking about this issue, the hardest part for us was to consider what topics to leave out, rather than what to include. With limited space, it has been extraordinarily difficult to choose just 10 articles for the issue. Our aim has been to cover as wide a view of the theme as possible, to give a flavour of just how diverse writing for patients can be and how many different skill sets are needed (part of the joy of it, for us!). We thank all the authors who have put aside some of their valuable time to write their articles.

Using not only difficult to understand terms, but also different terms to mean the same thing, can be very confusing for patients. With this in mind, a new global initiative has begun to try to establish a set of plain language terms used commonly in clinical research. The group behind this initiative is extremely diverse, and includes representatives from industry, the medical writing community, patient representatives, and academic institutions, among others. It is a highly ambitious and very exciting initiative and we are proud to present an article from some of the group (**Sylvia Baedorf Kassis et al.**) explaining the project and its aims. On a related topic, **Neil M. Davis** offers an interesting look at abbreviations that are used in multiple ways – potentially causing problems for professionals and patients alike.

Lisa Chamberlain James et al. discuss the issues surrounding writing for patients, including the new guidance and regulations instituted by regulatory agencies. The authors discuss the challenges and opportunities these pose and offer an insight into the possible future of writing for patients.

In the spectrum of information for patients, perhaps one of the biggest challenges is to provide fit-for-purpose, contextual information about Phase 1 clinical trials – when these involve healthy people, may not have a specific indication, and often involve medicines that never reach the market. With this in mind, **Clive M. Brown et al.** describe a template that the authors have developed to help writers to produce meaningful lay summaries of Phase I trials in healthy volunteers. The template ensures that study designs and endpoints are described in a consistent, lay-friendly manner across different types of Phase I trials.

Looking at patient information from a completely different perspective, **Alison Rapley** offers her insight into what makes a good (and bad!) participant information sheet. This is one of the documents submitted to research ethics committees for approval. Alison explains how to ensure that the document meets the necessary requirements by drawing on her first-hand experience as a research ethics committee member.

Development of a patient publication steering committee (PPSC) is an innovation in industry publication practices. **Linda Feighery et al.** describe how a pharmaceutical company plans to partner with patients to establish a PPSC and share insights on how medical writers could support such committees.

In a world increasingly overtaken by automation and artificial information, **Andrea Rossi** reminds us that although software can do word-to-word translation, there is much more to translation than just the words themselves. He explains the importance of communicating in a way that takes account of, and is sensitive to, the reader's culture.

Writing for the internet requires a slightly different

GUEST EDITORS

Dr Lisa Chamberlain James
Lisa@trilogywriting.com

Amy Whereat
amy.whereat@speakthespeech.fr

skill set than writing for print publications. Authors need to be aware of their potential audience's interests. To equip authors to write for the internet, **Diarmuid De Faoite** outlines the advantages that the Web presents and explains how to avoid mistakes.

Before the pandemic we are living with this year, most medical writers would have been right in thinking that writing for patients would be mostly limited to informed consents, laypersons summaries, and the odd patient engagement website. However, the events surrounding COVID-19 have brought the influence of social media under the spotlight. The WHO described the excessive amount of misinformation that bombarded media channels worldwide as an "infodemic". As if we needed another "-emic" this year… Nevertheless, **Sara Ferrão** explains how powerful social media has become in communicating healthcare information to the general public. She also makes some useful suggestions for health writers to keep in mind when reporting on peer-reviewed publications.

Along the same lines, **Amy Whereat** recounts a conversation she had with **Otto Spranger** following the 2019 spring conference in Vienna. Otto highlights the difficulties that patients still have in understanding the information that they need to make health decisions. He also suggests that medical writers, who understand the clinical trial process, can help patients to sift through the mass of clinical trial information that will soon become available with the mandatory publishing of layperson summaries.

We hope that there is something in this issue for everyone, and that you enjoy reading it as much as we have enjoyed putting it together and working with the truly inspiring authors. Even if regulatory writing is your one and only true love, we hope that this issue will give you an appreciation for the many facets of writing for other audiences and how worthwhile and rewarding writing for patients can be.

Stay safe, all.

Lisa and Amy

About the Guest Editors

Dr Lisa Chamberlain James is a Senior Partner and CEO of Trilogy Writing & Consulting Ltd. She has been a medical writer since 2000 and has worked in the regulatory and medical communications fields. Lisa has a special interest in writing for the general public, is a member of EMWA's Educational Committee, teaches and reviews workshops for the American Medical Writers Association, is a member of TOPRA, DIA, and PIPA, initiated the EMWA PV Special Interest Group, is chair of the Geoff Hall Scholarship Committee, and is a Fellow of the Royal Society of Medicine.

Amy Whereat has been a freelance medical writer for over 10 years. She writes clinical research publications and review articles for industry, academia, and patient associations.