

Partnering with patient associations: Engaging medical writers to support health literacy for patients

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Abstract

As patients are increasingly involved in healthcare decisions, there is a growing need for them to have access to appropriate health information. Medical writers, being a link between medical research and published data, are well placed to make medical research accessible for patients. Presented here is a discussion with Otto Spranger, patient advocate of the Global Allergy and Airways Patient Platform, Vienna, Austria, about access to clinical research data and the role of medical writers in improving health literacy.

What challenges do patients face in getting healthcare information today?

In recent years, the healthcare industry in Europe has faced growing challenges and pressure to effectively manage human health. The current population demographics are putting pressure on the sustainability of our health systems. New epidemics, such as coronaviruses, put peaks of pressure on hospital and community care, and new technologies such as artificial intelligence and e-health are revolutionising the way health is managed.¹

In this context, patients are taking on increasing responsibility for their health in a situation where they have less time with their traditional information source, their doctors. This lack of health information support is driving patient hunger for health news and information. However, for a patient to be empowered to make

sound health decisions, they need to be sufficiently informed and health literate. Yet, many patients lack sufficient health literacy to understand the information to make these health decisions. Although the level of health literacy worldwide is improving, many patients still have difficulty obtaining and understanding health information. One such problem is access to clinical research data. Many patients find themselves lost in a plethora of information that is difficult for them to understand and relate to their health issues.

What challenges do patients face in accessing clinical research data and how does it impact treatment?

In recent years, access to clinical research data has improved remarkably. Researchers in both academia and industry have been making clinical documents and datasets available through various independent portals such as clinicalstudydatarequest.com, yoda.yale.edu, clinicaltrials.gov, EudraCT, ICTRP, and other publicly available, sponsored websites.

More recently, the (EU) Clinical Trials Regulation No 536/2014

formalised clinical research data access by requiring sponsors to make layperson summaries available on a European Medicines Agency portal and database. These layperson summaries describe the designs and results of individual clinical studies using plain language, figures, and pictograms.

They are written for interested readers with limited health literacy or scientific expertise to help them understand clinical study results.³ Although this will provide easier access to clinical research data, it will also create a problem for interested readers who will then need to deal with the vast volume of mostly industry-sponsored data. The public will also have to learn how to place individual trial results into the overall research context, which raises another issue: the lack of independent academic research.

Currently, a large proportion of clinical research studies are run by industry. Although the EU actively supports basic research, more independent clinical research is needed. A particular example is in the field of allergies. In recent years, few innovations have appeared in this field and most interventions only treat symptoms. This lack of basic and clinical research means that information about the treatment of asthma or other respiratory diseases is limited. This lack of balanced information is particularly problematic for both patients and general practitioners, who need to understand the underlying disease process and appropriate treatment.

A clear example of this is the current overuse of short-acting beta 2 adrenergics (SABAs). Inhaled SABAs have been a part of first line and emergency treatment for 50 years and both doctors and patients appreciate this treatment it provides rapid symptom relief. But then, patients begin to rely on symptom relief and often

discontinue the background inhaled corticosteroid therapy that prevents the underlying inflammation. One reason for this is some patients are anxious about taking cortisone. Hence, this results in situations today where patients do not always take their asthma medication correctly and this is leading to unnecessary deaths. The Global Initiative for Asthma (GINA), a joint programme involving international stakeholders, is determined to improve asthma treatment.⁴ The GINA reports provide physicians with an up-to-date review of the literature and evidence-based strategies that can be easily implemented in clinical practice to help improve asthma treatment.

What are the current patient needs?

There is a current need to educate patients after diagnosis about medication. Patients need to take their medication, have good lifestyle habits, and



avoid behaviours that may worsen their disease, even if they are feeling well. In asthma, learning to use the inhaler correctly to fully benefit from the medication is important. Yet in the UK alone, almost two-thirds (65%) of people with asthma do not receive primary care from a healthcare professional, which includes an annual review and a check to ensure they are using their inhaler correctly. There is a need to ensure that clinicians follow treatment guidelines, and that patient preferences be included into practice guidelines.⁵ Also, more patients need to become better informed about their condition and how to manage it best. The improvements made in patient management in the diabetes field could be a benchmark for other disease areas.

What advice do you have for medical writers?

Medical writers as communicators of medical research play a key role in making medical

research data accessible for patients and help them to sift through misinformation. They can become involved with industry-sponsored websites or web-based services destined for patients, families, and carers. When publishing protocols or research data, medical writers can keep the patient in mind since patients also have access to public databases and may need assistance to understand the impact of these data on them. Also, medical writers can

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help to place the research data in context of the overall clinical research process.

Medical writers have close contact with researchers. This means that they are well-placed to encourage authors of both academic and industry studies to publish research. This may be particularly important for trials where the endpoint is not met or for subpopulation analyses that show a strong activity of interest to patient association members, even though they may have less priority for industrial partners who

may be more focused on registration and reimbursement.

Medical writers understand the clinical research process and as storytellers are well placed to educate patients. Working with patient associations, medical writers can help educate patients to disseminate truthful information. This may involve explaining a disease process, treatment, or where a study may fit and what the results of a given trial may mean to them. They can also ensure that trial reporting is balanced and that ethical standards are maintained.

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