



Dear all,

Having left the office for 5 days to go to the EMWA Spring Conference, I returned to the obligatory email avalanche. While it was mostly junk (and unfortunately still no 'congratulations on winning the lottery' message...), there were some messages from friends I had just seen at the conference, and this reminded me again what a special organisation EMWA really is. I have spent a long time doing 'the conference circuit' both as an academic and as a medical writer covering meetings and helping to create them, but I have never before come across an organisation that can offer excellent training, great networking, and the chance to meet people so open and willing to help others in their field. That all of this is done voluntarily by the workshop leaders and members of the EMWA committees is just astounding, but is testament to how much

EMWA means to everyone involved. This year's Spring Conference was another record breaker – over 400 delegates attended and the theme was 'Health Economics and Market Access'. There were some fantastic symposia throughout the week, and the opening session was a MedComms Networking event, run jointly by EMWA and Network Pharma Ltd: 'Better communication means better patient outcomes: vision or illusion?'. This session also let us all play with some gadgetry – IML hand-held keypads that allowed delegates to interact directly with the session chair, asking questions, making comments, or answering questions set by the panel. Great fun, and obviously with a valuable application for meetings (when not in the hands of a bunch of medical writers!).

For anyone unable to get to the Spring Conference this year, this section has a brief summary of this really interesting session. I hope you find it useful, and I hope to see you in Barcelona in November!

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EMWA Spring Conference 2013 – Networking Event and Welcome Lecture

Better communication means better patient outcomes: Vision or illusion?

This session was led by Mark Duman, Director of MD Healthcare Consultants and Chair of the Patient Information Forum (PiF). The audience was introduced to the IML keypads and in a few clicks of the buttons it was established that the audience was composed of 89% EMWA members, and in terms of main work areas, 27% of the audience were 'regulatory/CRO writers'.

Mark then introduced the panel: Eveline Wesbyvan Swaay (a Global Safety Physician from AstraZeneca), Ben Bridgewater (a Consultant Cardiac Surgeon from University Hospital of South Manchester), Paul Woods (a Compliance and Ethics consultant, ex-AstraZeneca and previous Chair of the European Federation of Pharmaceutical Industries and Associations [EFPIA] Information to

Patients Task Force), and Jane Lamprill (who runs a paediatric research consultancy).

Mark started by asking the audience if they were 'patients'. In all, 53% said 'no' (10% 'didn't know!'), and he explained that we are *all* potential patients (the panel included) – a very important point considering the topic of the session. He explained that consumer health information (CHI) concerns helping patients and the public make informed decisions about their lifestyle and well-being, their medical conditions and treatments, and their choice of provider (a new concept in the UK). In all, 41% of the audience had never worked on CHI, but Mark explained that the quality of the information provided to patients is vital in effecting positive outcomes; preventing diseases, and allowing patients to control their health.

The PiF has produced a report showing the power of high-quality information, but there are still many challenges: CHI is not integrated into patient care provision, there is a lack of quality standards, a low level of investment, too much duplication, a

focus on measuring provision rather than outcomes, and a lack of recognition of the expertise required. In addition, clinicians have very little ongoing education about communication skills, and there is not enough acknowledgement that 'one size' does not fit all patients. This was confirmed by the audience, who returned a wide range of answers to the question 'how well informed were you the last time you had to make a medical decision?'

Paul Woods explained that EFPIA aims to promote factual, non-promotional information, and suggested that in the future, medical writers could use their skills in social media, as well as in traditional formats, to provide non-promotional information to patients. He suggested that in pharmaceutical companies, medical departments should assume responsibility for patient information rather than marketing departments.

Eveline Wesby-van Swaay outlined the difficulties of explaining medical information to patients, which are caused by the variety in patients' ability to understand and interpret medical data. She stressed that information should be tailored to individuals as much as possible, and that the drop in MMR vaccination rates is a good example of how important it is to explain scientific data to patients clearly and in a non-promotional way. Eveline proposed that if Andrew Wakefield's study had been properly explained to the general public, the MMR vaccine may not have received such a negative response.

Ben Bridgewater concurred, and has found that the public have a huge appetite for scientific and medical data. His own experience is in the publication of cardiac surgery outcomes and the transparency in this area has led to decreased mortality rates and improved cardiac outcomes. Such transparency is being embraced in the UK. However, Ben emphasised that information must be contextualised for patients; they should not just be given 'raw data'.

Jane Lamprill discussed information about clinical trials for children, their parents and grandparents, and stressed the importance of targeting information appropriately. This is particularly difficult in paediatric studies because there may be a wide variety of reading and cognitive ages in the children involved; in fact, the Organisation for Economic Co-operation and Development has

shown that 20% of all 15 year olds have reading difficulties. Words and phrases with more than one meaning for children are particularly difficult e.g. study, trial, and genetic makeup. However, Jane also agreed that better information equated with improved patient outcomes.

The panel was asked if they thought that the pharmaceutical industry could be trusted to give correct information. All the panel members believed that good medical writers were needed, but thought that the problem may lie with 'overzealous' marketing departments. Thinking specifically about package inserts, the panel stressed that it was important to consider patients' needs, as well as those of the regulators, and they felt that the pharmaceutical industry (and clinicians) must earn public trust by increasing their transparency.

Although risk-benefit information can be very difficult to explain, the panel recommended giving different 'levels' of information, so that patients can decide for themselves on the level of detail required. For example, when the MMR vaccine was publicly questioned by Andrew Wakefield, none of the caveats or assumptions made in his study were explained to the general public, and so they did not have the 'full story' to enable them to make an informed decision. Furthermore, the panel believed that it is important to think carefully about how information is presented to patients, e.g. number needed to treat figures should be communicated very carefully and explained so that they are put in context. It should also be noted that an informed patient is not always an obedient patient!

Finally, the panel was asked if they believed that times are changing with respect to transparency and firewalls, and they all agreed that they are. They believed that the pharmaceutical industry is trying to 'do the right thing' and to be a responsible partner in healthcare, and that regulators are thinking of safety first.

The session ended with a final 'key pad' question – how the audience had rated the value of the session. The answer? Most rated it over 8 out of 10 – a commendable score from a very thought-provoking opening session.

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