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Can Social Media Benefit Drug Safety?

I have read the article by Edwards and Lindquist[1] published in *Drug Safety* and would like to take the chance to comment on the situation they describe, from the perspective of a drug safety manager of a pharmaceutical manufacturer.

The dissemination of information with regard to adverse reactions to a pharmaceutical compound has undergone several changes over time. There is a trend that more and more media are coming into use where the reporter remains anonymous, such as email to companies using general email accounts, or even media such as Facebook, Twitter or others. We have to consider the balance between the right to freedom of communication and information and the responsibility of each individual to contribute to the health protection of their community.

Of course these media may be useful tools for screening what is happening in the community, but this kind of data and the quality of the data must also be taken into account when considering any further regulatory decision. In my understanding, there is an urgent need for initiatives such as ICH or CIOMS to consider how the process of safety evaluation can use these data in a global environment. Currently, pharmaceutical manufacturers are facing the problem of handling each case as a single case report, knowing the fact that:

- regularly there is no chance for follow-up;
- duplicates cannot be identified as users may have different multiple profiles on the Internet;
- information on special issues may create a 'hype' in user communities, leading to reporting on issues that happened years before, causing them to appear as an actual and emergent situation.

Furthermore, we should talk about intended misuse of these media, such as directed publishing of positive or negative information for different purposes, e.g. damaging the image of a product or creating rumours in media to impact on compensation trials against a manufacturer, etc.

The media that are created on a global platform using English as the basic language further create the risk of the loss of relevant information, such as the ethnic background of a reporter. These media are used by people around the world, and not knowing the country of origin may lead to misinterpretation of information, for example, particular drug effects for certain populations may already be known.

In addition, drug regulatory authorities must have an interest in receiving valuable information to fulfil their responsibility and to distinguish this properly from all other sources where the quality of data is too limited. Therefore, I think we need a clear strategy to distinguish between data we use for a valid individual case safety report (where I believe the valid identification of the reporter to enable follow-up is essential), and those data gathered from the above-mentioned media as a source that could give a signal for items to be investigated further.

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Dr Franzen is an employee of Takeda Pharma GmbH, Germany. The content of the letter does not represent an official company position but is a private response.

Reference

1. Edwards IR, Lindquist M. Social media and networks in pharmacovigilance: boon or bane? Drug Saf 2011; 34 (4): 267-71

The Author's Reply

I am pleased that Dr Franzen has responded in such a helpful way. He has put some flesh on the bones of my concerns about the Internet, from the perception of those who have a keen interest in good and bad information circulating on their products.

I liked the conclusion that information on the Internet that cannot be validated as to source nor followed up, should be grouped into a pool of indicative information to be investigated further. I would have thought that if drug regulators could agree on such a loose but pragmatic approach, it could save a good deal of money and wasted effort.

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