

Responsible dissemination of research within the pharmaceutical field

The Danish Society for Pharmacoepidemiology has formulated a number of guidelines for researchers when communicating their research results to the news media.

Background

Publication of new pharmacoepidemiology studies can incite substantial media interest, given the widespread implications of such studies to population health. Often, the authorities are asked to make a rapid assessment of the new studies, and physicians in general practice receive inquiries from patients who want to know if results of a particular study have implications for their treatment. Pharmacoepidemiology studies may report on previously unknown side effects of a widely used medicine, or may provide new evidence of beneficial effects of medicines. Selective reporting, or the exaggeration of results from poor quality research, can incite unnecessary worry to citizens and burden the healthcare system. Such skewed/biased press reporting can prompt patients to stop taking essential medicine or take medicine that are not recommended. It is therefore important for public health that new research findings are disseminated to the public in a responsible manner. In Denmark, freedom of speech and freedom of the press is inherent in our democratic society. It facilitates a much-needed foundation for an open discussion of research findings. Everyone has the right to discuss research results in the press. Naturally, patients and their relatives also follow such discussions on health research. However, these individuals may not always have sufficient prerequisite knowledge to equip them with the ability to critically evaluate the research findings and perspectives. It is therefore important that health professionals are aware of this responsibility before disseminating their research to the press. This responsibility involves communicating research honestly and in a way that avoids igniting any unnecessary concern.

Due to recent debate on research dissemination, the Danish Society for Pharmacoepidemiology has drawn up a number of guidelines for researchers and institutions, when assessing whether or not their study is of interest to the news. These recommendations are inspired by a specially commissioned seminar, which was held in collaboration with the Danish Medicines Agency in the autumn of 2018. Several stakeholders participated in the seminar.

Many factors can influence the framework for good research communication including how a given university educates its researchers on dissemination of research results, the experience level of a given journalist, the extent of collaboration between a given journalist and scientific journal, and the individual researcher's need for visibility in terms of obtaining research funding. However, the starting point for the following guidelines is that the conditions for disseminating research findings are acknowledged as they currently exist, and that these cannot be changed immediately by the individual researcher.

Before publication

- Inform the health authorities that your study will soon be published and that you believe that it will incite public interest. Oftentimes, authorities are asked to explain the implications of a given research finding to citizens and patients on the day the research is published—when a new study makes headlines. Therefore, it is important to make the authorities aware of the study before publication. Please send the study to the authorities at least a week in advance of publication so that the appropriate professionals have the opportunity to read and evaluate it. In this way, the authorities have the best possible opportunity to consider and comment on the perspectives of the research findings. The Danish Medicines Agency will often be asked to assess whether the study is expected to have any consequences for the use of the drug, for example if the drug should be withdrawn from the market. The National Board of Health will often be asked to answer whether treatment guidelines should be changed.
- Ensure that there is consensus in the co-author group on the main message of the study, and discuss the content of the press release in the co-author group before sending it.
- Many research institutions have made guidelines for responsible research dissemination. It can therefore be a good idea to prepare a press release in collaboration with the communication department at your institution. The press release is your opportunity to present the study's main findings and conclusions. The press release should be written briefly and in an easy-to-understand language. Absolute figures and absolute risks are often preferable to relative numbers. Relative risks should as a rule never stand alone. Some journalists directly reproduce the press release, others quote from the press release, and others may even write an article themselves, but may have become aware of the study based on the press release. The press release serves as an invitation to journalists to contact you, with a view to follow up questions, which you should be willing to answer.
- Assess what the research results mean for citizens and patients. Ensure that your press release reflects the possible gain or risk as precisely and as explicitly as possible.
- Pretest your press release: Let one or more layperson who is not familiar with the research read it and ask them to state how worried they would be if the research results were directly related to them. Check if their assessment is in line with your perception of how you feel your results should be perceived.
- Inform the professional societies for which the study is relevant. It will very often be the Danish College of General Practitioners, as the general practitioners will often be the first to be contacted by concerned patients. Other professional societies may also be relevant to contact depending on the study's concrete conclusions. Irrespective of the society, inform them in good time and make room for input from stakeholders to be included in your press release.
- Inform any patient associations for whom the study findings are relevant, so that they can prepare a news segment on their website, targeting their members.
- Have an approximation of how many, and which type, of patients the research findings are relevant to. It is important that you spend time specifically distinguishing the relevant drugs so that the study findings are not reproduced as an overly broad group in the media, for example as "heart medicine" or similar.
- In your press kit, suggest other researchers who can provide perspective on the results of your study. If necessary, send your study and press release to these other researchers so that they are also prepared for press inquiries.

- If you choose to actively contact the press yourself, choose the journalists you contact with care. Think about how you can simplify your message and whether you need to create a form of press kit. Your message will certainly be simplified in the daily press. You are more likely to be able to simplify it yourself in the most responsible way, rather than leaving it entirely to the media.

On the day of publication

- Be honest if your study represents a single study in a given field. New knowledge should be taken in the context of all the previous research. A single new study can rarely stand-alone. Beware of interpreting the potential consequences of your study findings yourself as you may give a biased view after having worked on the study for a long time.
- Be realistic about the level of importance of your study findings.
- Be aware that your research can easily create worry or hope in patients.
- Clear your calendar and spend time talking to journalists on the day of publication. Once you have been in the media once, other media will contact you for interviews. It is a good idea to participate actively to ensure that any information related to your study is correctly interpreted and accurately disseminated in a balanced manner.
- When interviewed by journalists for the printed press, ask to see your quotes before publication. Some journalists will gladly send you the entire article, while others will only send your quotes for review.
- Allocate time in your calendar to keep abreast of the press and social media so that you have the opportunity to respond quickly and intervene if your results are rendered incorrectly. Get others to help you if you are too busy answering press inquiries.
- Remember that if you go to the press, you will probably be asked immediately what the consequences of the study will be in the future. For example, whether patients should stop their medication or start a medication for a purpose other than that approved. Be ready to answer questions by referring to the relevant authorities and be clear if there is no reason why the patients ought to act urgently.

In the days after publication

- Allocate time during the day, and in the following days to contact the media outlet to correct any factual errors, misunderstandings or exaggerations in the media coverage. Keep in mind that web articles are shared extensively on social media and are available online for a long time. It may therefore be worthwhile to intervene and correct errors or misunderstandings.
- Allow time to respond to social media inquiries. Here it may be particularly important that you clearly identify yourself as the researcher behind the study so that your comments can be distinguished from others.